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In the Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

PETITION FOR A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

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10 pp

QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, prohibits a hospital program receiving federal financial assistance from withholding nourishment or medically indicated treatment from a handicapped child, or otherwise discriminating against the child, solely because of his handicap.

PARTIES TO THE PROCEEDING

The petitioner is Margaret M. Heckler, the Secretary of Health and Human Services.

The respondents are the plaintiffs in two suits filed in the district court that were consolidated in that court and in the court of appeals. The plaintiffs in *American Hospital Association, et al.* v. *Heckler* are the American Hospital Association, the Hospital Association of New York State, and Strong Memorial Hospital of the University of Rochester. The plaintiffs in *American Medical Association, et al.* v. *Heckler* are the American Medical Association, the American Hospital Association, the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Acadamy of Family Physicians, and Drs. Hubert A. Ritter, Peter A. M. Auld, Rita Gilman Harper, and Roy Howard Petrie.

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No.

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v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

PETITION FOR A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

The Solicitor General, on behalf of the Secretary of Health and Human Services, petitions for a writ of certiorari to review the judgment of the United States Court of Appeals for the Second Circuit in this case.

OPINIONS BELOW

The order of the court of appeals summarily affirming the judgment of the district court (App., *infra*, 1a-3a) is not reported. The prior opinion of the court of appeals in *United States* v. *University Hospital of the State University of New York at Stony Brook* (App., *infra*, 4a-47a), upon which both the district court and court of appeals relied in this case, is reported at 729 F.2d 144. The memorandum and order of the district court (App., *infra*, 48a-49a) are reported at 585 F. Supp. 541.

JURISDICTION

The judgment of the court of appeals was entered on December 27, 1984. The jurisdiction of this Court is invoked under 28 U.S.C. 1254(1).

STATUTE AND REGULATIONS INVOLVED

1. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, provides:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulation may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

2. 45 C.F.R. 84.55 and 45 C.F.R. Pt. 84, App. C, as added by 49 Fed. Reg. 1650-1654 (Jan. 12, 1984), are reproduced in the appendix to this petition (App. *infra*, 53a-72a).

STATEMENT

1. a. On April 30, 1982, following public disclosure of an incident in Bloomington, Indiana, in which a newborn child with Down's Syndrome was permitted to starve to death after being denied life-saving surgery to repair a blocked esophagus, the President directed the Secretary of Health and Human Services to remind health care providers receiving federal financial assistance that Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap in programs or activities that receive federal financial assistance. See 49 Fed. Reg. 1622-1623 (1984); *American Academy of Pediatrics* v.

Heckler, 561 F. Supp. 395, 397 (D.D.C. 1983). On May 18, 1982, the Secretary sent such a notice to all covered health care providers. 47 Fed. Reg. 26027. The notice stated that "[t]here has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects" and that "[r]eports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome." *Ibid.*

Subsequently, on March 7, 1983, HHS promulgated interim final rules establishing certain procedures relating to the application of Section 504 to refusals to treat handicapped infants. 48 Fed. Reg. 9630. On April 14, 1983, these regulations were invalidated by the United States District Court for the District of Columbia in *American Academy of Pediatrics* v. *Heckler*, *supra*. Although the district court in that case was of the view that the broad language of Section 504 might well authorize some regulation of the provision of some types of medical care to handicapped newborns (561 F. Supp. at 402), it concluded that HHS's decision to waive the public comment period when it promulgated the regulations violated the Administrative Procedure Act and that the regulations were arbitrary and capricious because the administrative record failed to establish that several important factors had been adequately considered (*id.* at 403-404).

b. The Secretary then published new proposed regulations on July 5, 1983. 48 Fed. Reg. 30846. After receiving broad public comment,[1] the revised final regulations at issue here were published on January 12, 1984. 49 Fed. Reg. 1622.

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[1] HHS received almost 17,000 comments on the proposed regulations, more than 97% of which were favorable. 49 Fed. Reg. 1622-1623 (1984).

The regulations explain the basic applicability of Section 504 in this setting through interpretative guidelines, which establish four basic principles: (1) health care providers receiving federal financial assistance "may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment"; (2) treatment that is futile or will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant for purposes of Section 504; (3) reasonable medical judgments in selecting among alternative courses of treatment will be respected; and (4) where a parent withholds consent to treatment that is medically indicated, the hospital may not, solely on the basis of the infant's handicap, decline to report the matter to the appropriate child protective agency or to seek judicial review. 45 C.F.R. Pt. 84, App. C para. (a)(1)-(4).[2] The remainder of the regulations contains measures for the implementation of these principles.

The implementing regulations are tailored in a number of respects to foster a cooperative effort on the part of the federal government, state governments, the medical community, and private advocacy groups. For example, the

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[2] The interpretative guidelines also give illustrations of conduct that would and would not violate Section 504. For example, the guidelines reiterate the Department's position that withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome, when the withholding is based upon the anticipated future mental retardation of the child and when there are no medical contraindications, would constitute discrimination in violation of Section 504. But the guidelines also state that withholding of treatment for such conditions as anencephaly, spina bifida, and severe prematurity and low birth weight—when based on reasonable medical judgments that the treatment would be futile, too unlikely of success given complications in the particular case, create risks of potential harm to the infant, or merely prolong the act of dying—would not violate Section 504. 45 C.F.R. Pt. 84, App. C para. (a)(5)(i)-(iv).

regulations initiate new efforts to make the use of federal enforcement mechanisms unnecessary by encouraging hospitals to establish their own policies and procedures to implement the guiding principles. This approach follows the recommendation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 49 Fed. Reg. 1622, 1623-1625 (1984). In accordance with this recommendation, the Secretary developed a model for hospitals that wish to establish Infant Care Review Committees to assist in evaluating issues relating to the treatment of handicapped infants. 45 C.F.R. 84.55(a) and (f).

Under the proposed model, the Infant Care Review Committee [3] would develop and recommend to the hospital institutional policies concerning the withholding or withdrawal of treatment from infants with life-threatening conditions, including guidelines for management of certain categories of cases (*e.g.*, Down's Syndrome and Spina Bifida) and procedures to be followed in certain recurring circumstances (*e.g.*, brain death and parental refusal to consent to life-saving treatment). 45 C.F.R. 84.55(f)(3)(i). The Committee also would review specific cases where a preliminary decision has been made to withhold or withdraw life-sustaining treatment from patients in certain categories or where there is a disagreement between the treating physician and the family regarding such treatment, and the Committee would recommend that the hospital refer the case to an appropriate court or child protective agency if the Committee disagreed with the family's refusal to consent to treatment in a particular case. 45 C.F.R. 84.55(f)(3)(ii). In addition, the Committee would conduct a retrospective re-

[3] The Committee would be composed of a practicing physician, a practicing nurse, a hospital administrator, a representative of the legal profession, a representative of a disability group or a disability expert, a lay community member, and a member of the hospital's organized medical staff, who would serve as chairman. 45 C.F.R. 84.55(f)(2).

cord review of cases in which treatment had been withdrawn or withheld, in order to determine whether such instances were consistent with the hospital's policies. 45 C.F.R. 84.55(f)(1)(iii).

In accordance with the policy of involving state agencies in the process as well, the regulations require each state child protective services agency that receives federal financial assistance to establish methods of administration and procedures to assure that it utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants. 45 C.F.R. 84.55(c). These methods and procedures must include a requirement that health care providers report circumstances that they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants; provisions for the state agency to review and, if necessary, investigate such reports; procedures for affording child protective services to medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the furnishing of necessary nourishment and medical treatment; and notification to HHS of each report of suspected medical neglect of an infant solely because of his handicap, including the nature of the state agency's investigation and final disposition of the matter. *Ibid.*

Finally, in order to facilitate investigation by HHS where necessary, the regulations provide for expedited access to records and facilities of the recipient hospital for investigative purposes when "necessary to protect the life or health of a handicapped individual." 45 C.F.R. 84.55(d). Similarly, when immediate action is necessary, the regulations allow for waiver of the usual 10-day waiting period prior to the initiation of judicial or other action to effect compliance. 45 C.F.R. 84.55(e). An appendix to the regulations sets forth guidelines for HHS investigations of reports of unlawful withholding of medical treatment, including provisions for consultation with the hospital's Infant Care Review Committee and meas-

ures to insure that any investigations are conducted promptly and with the least disruption possible. 45 C.F.R. Pt. 84, App. C. para. (b). The regulations also require recipient hospitals to post a notice, visible to nurses and other medical professionals, which (i) states that Section 504 prohibits the withholding of nourishment and medically beneficial treatment from handicapped infants based solely on their present or anticipated mental or physical impairments, and (ii) identifies the designated hospital official, the appropriate child protective services agency, and the HHS office that may be contacted to obtain further information or to report suspected noncompliance. 45 C.F.R. 84.55(b).

2. a. On April 6, 1983 the American Hospital Association, the Hospital Association of New York State, and Strong Memorial Hospital filed suit in the United States District Court for the Southern District of New York challenging the initial regulations that were promulgated by the Secretary on March 7, 1983. See page 3, *supra*. The district court entered a temporary restraining order barring enforcement of those regulations in New York State. *American Hospital Ass'n, et al.* v. *Heckler*, 83 Civ. 2638-CLB (Apr. 6, 1983). However, before a hearing could be held by the district court below, the United States District Court for the District of Columbia declared the regulations invalid on APA grounds in *American Academy of Pediatrics* v. *Heckler*, discussed at page 3, *supra*. On March 12, 1984, after the Secretary promulgated the new regulations at issue here, the plaintiffs filed an amended complaint challenging those regulations as beyond the Secretary's authority under Section 504. On the same date, a second suit was filed in the District Court for the Southern District of New York by the American Medical Association, the American Hospital Association, and others challenging the same regulations. The two suits were consolidated in the district court.

By memorandum and order dated May 23, 1984, the district court held that the regulations are beyond the

Secretary's statutory authority under Section 504 (App., *infra*, 48a-49a). In so holding, the court concluded that this case was directly controlled by the Second Circuit's decision in *United States* v. *University Hospital of the State University of New York at Stony Brook*, 729 F.2d 144 (1984) (App., *infra*, 4a-47a), discussed at pages 8-11, *infra*. On June 11, 1984, the district court entered its final judgment, which permanently enjoined the Secretary and her officers, agents, employees, and attorneys from any further implementation of the regulations and from taking any other action under Section 504 (including any pending investigation or other enforcement action) to investigate or regulate treatment decisions involving impaired newborn infants in any program receiving federal financial assistance (App., *infra*, 50a-52a).

b. In a brief per curiam order dated December 27, 1984, the court of appeals summarily affirmed the district court's judgment on the basis of the court of appeals' prior decision in *United States* v. *University Hospital* (App., *infra*, 1a-3a).[4]

3. a. In *United States* v. *University Hospital*, which both the district court and court of appeals regarded as controlling in this case, a divided panel of the Second Circuit held that Section 504 is wholly inapplicable to the withholding of medical treatment from handicapped infants. The court therefore held that the government was not entitled under existing regulations (45 C.F.R. 80.6(c), 84.61) to access to the hospital's records pertaining to a particular handicapped infant, Baby Jane Doe. HHS had received a complaint that Baby Jane Doe was being discriminatorily denied life-saving medical treatment on the basis of her handicap, and it sought

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[4] The Secretary recognized that this case was controlled in the court of appeals by the prior decision in *University Hospital*, and she therefore moved for initial en banc consideration of the instant case. The court of appeals denied that motion on August 22, 1984. The Secretary then moved for summary disposition of the appeal.

access to her medical records in order to investigate whether a violation of Section 504 had occurred.[5]

The court of appeals in *University Hospital* assumed, without deciding, that the hospital's receipt of Medicare and Medicaid funds constituted the receipt of "Federal financial assistance" that triggered the application of Section 504 to the withholding of medical treatment from Baby Jane Doe (App., *infra*, 16a-18a). Further, the court held that Baby Jane Doe was a "handicapped individual" for purposes of Section 504 (*id.* at 26a-28a). However, the majority held that Baby Jane Doe could not be considered to be an individual who was "otherwise qualified" for the hospital's services or was "subjected to discrimination" within the meaning of Section 504 (*id.* at 28a-39a).

According to the majority, "the phrase 'otherwise qualified' is geared toward relatively static programs or activities such as education, employment, and transportation systems. As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning" (App., *infra*, 30a (citations omitted)). Nor, in the majority's view, could the child be considered to be "subjected to discrimination," because "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a

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[5] Baby Jane Doe was born on October 11, 1983, with multiple birth defects, including myelomeningocele (exposed spinal cord membranes, commonly known as spina bifida), microcephaly (abnormally small head), and hydrocephalus (accumulation of fluid in the cranial vault). On advice of her initial pediatrician, Baby Jane Doe was admitted to University Hospital for corrective surgeries. After consulting with physicians at University Hospital, her parents withheld consent to surgeries to treat the spinal defect and to drain the water from the infant's skull, opting instead to administer antibiotics and dress the exposed spinal sac. University Hospital acquiesced in that decision. See *United States* v. *University Hospital of the State University of New York at Stony Brook*, 575 F. Supp. 607, 610 (E.D. N.Y. 1983).

particular decision was 'discriminatory'" (*ibid.*). The majority also declined to attach significant weight to the Secretary's interpretation of Section 504 in this setting, terming the regulatory history "inconclusive" (*id.* at 25a; see generally *id.* at 18a-25a). In addition, the majority read the legislative history to reflect a congressional concern primarily with access by the handicapped to federally assisted programs, and it relied on the absence of a specific statement in the legislative history that Section 504 applies to medical treatment decisions (*id.* at 31a-38a). Finally, the majority concluded that to require a hospital to petition a state court or to take other steps to override the parents' withholding of consent to treatment in a particular case would impose an "affirmative action" burden on the hospital, contrary to this Court's decision in *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979) (App., *infra*, 39a).

b. Judge Winter dissented (App., *infra*, 42a-47a). He concluded that because Congress explicitly patterned Section 504 after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d *et seq.*, which prohibits discrimination on the basis of race in federally assisted programs, Congress had determined that, "so far as the administration of federal financial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race" (App., *infra*, 43a-44a). Judge Winter stressed that the government has never taken the position that it is entitled to override a medical judgment; "[i]ts position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment" (*id.* at 44a). Based on the statutorily mandated analogy to racial discrimination, Judge Winter concluded that the logic of the government's position is "about as flawless as a legal argument can be" (*ibid.*):

> A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment.

> So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. Finally, once the legislative analogy to race is acknowledged, the intrusion on state authority becomes insignificant.

Accordingly, Judge Winter would have reversed the judgment of the district court in *University Hospital* and remanded for a determination whether the hospital was a recipient of "Federal financial assistance" that triggered the application of Section 504 to the infant (*id.* at 47a).[6]

REASONS FOR GRANTING THE PETITION

The court of appeals has held that the Secretary's regulations and interpretative guidelines concerning the application of Section 504 to the withholding or withdrawal of nutrition or medically beneficial treatment from an infant solely by reason of his handicap are invalid on their face. The court has held, in other words, that Section 504 does not apply to this entire category of cases, no matter how egregious the circumstances. Thus, to use one of the specific examples cited in the Secretary's interpretative guidelines,[7] Section 504 does not, in the court of appeals' view, prohibit a federally assisted hospital program from withholding life-saving surgery to correct an intestinal obstruction in an infant with Down's Syndrome, even if the hospital would not hesitate to perform the same surgery

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[6] Shortly after the court of appeals rendered its decision in *University Hospital*, the hospital disclosed that Baby Jane Doe had received corrective surgery for her life-threatening conditions (see page 5, *supra*) and had been discharged from the hospital. Accordingly, the United States elected not to petition for a writ of certiorari to review the judgment in that case.

[7] See 45 C.F.R. Pt. 84, App. C para. (a) (5) (i).

on a normal child and the hospital's failure to perform the surgery is based solely upon the mental retardation of the infant and thus solely upon his handicap.

The court of appeals' holding is flatly inconsistent with the language and purposes of Section 504 and with the Secretary's implementing regulations and interpretative guidelines, which are entitled to substantial deference. Nor does such an implied exception for all decisions concerning medical treatment of impaired newborn infants find any support in the legislative history of Section 504, which manifests an intent to adopt a broad bar to discrimination against the handicapped in federally assisted programs, specifically including those furnishing health services. Yet the court of appeals in this case has affirmed a sweeping nationwide injunction that purports to bar the Secretary from undertaking *any* investigation or enforcement actions under Section 504 with respect to *any* treatment decisions involving handicapped newborn infants in *any* program or activity receiving federal financial assistance. What is more, the court of appeals' view that Section 504 does not address decisions concerning the furnishing of medical treatment is not logically limited to infants whose impairments are severe, or even to infants. By thus suggesting that any decision by a physician or hospital relating to medical treatment is cloaked with blanket immunity from scrutiny under Section 504, the decision below calls into question the application of Section 504 to the furnishing of federally assisted health services to handicapped individuals generally. Review by this Court therefore is plainly warranted.

1. a. The starting point of analysis must of course be the language of Section 504 itself, for "we assume 'that the legislative purpose is expressed by the ordinary meaning of the words used.'" *Kosak* v. *United States*, No. 82-618 (Mar. 21, 1984), slip op. 5, quoting *American Tobacco Co.* v. *Patterson*, 456 U.S. 63, 68 (1982). See *Consolidated Rail Corp.* v. *Darrone*, No. 82-862 (Feb. 28, 1984), slip op. 7-9. Contrary to the court of appeals' view

(App., *infra*, 28a-31a), the language of Section 504 clearly prohibits a hospital program receiving such federal financial assistance as to bring it within the scope of the statute (see note 12, *infra*) from withholding nourishment or medically indicated treatment from a handicapped infant solely by reason of his handicap. Section 504 provides in relevant part:

> No otherwise qualified handicapped individual in the United States * * * shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance * * *.

The court of appeals in *University Hospital* held that an impaired newborn child is a "handicapped individual" for purposes of Section 504 (App., *infra*, 26a-28a). Although the court of appeals expressed reservations even about that conclusion—believing that the term might be understood to apply only to adults (*id.* at 26a-27a)—the statutory language in our view is so clear as to admit of no other interpretation.

The broad directive that "[n]o * * * handicapped individual" may be discriminated against itself suggests an all-inclusive coverage, without regard to the individual's age. Compare *North Haven Board of Education* v. *Bell*, 456 U.S. 512, 520 (1982). Moreover, the term "handicapped individual" is defined in broad terms to mean "*any person* who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C. 706(7)(B) (emphasis added). Especially in light of the Secretary's 1977 regulations implementing Section 504 (see 42 Fed. Reg. 22677), there can be no question that the infants who are the subject of the concern giving rise to the regulations at issue here have "physical or mental impairment[s]" (App., *infra*, 26a)[8]

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[8] HHS regulations define the term "physical or mental impairment" to mean "(A) any physiological disorder or condition, cos-

and that those impairments substantially limit one or more of the infants' "major life activities." [9] Moreover, as the court of appeals observed (App., *infra*, 27a), "it would defy common sense" to rule that the Baby Jane Doe involved in *University Hospital* was not at least "regarded" by others as having such an impairment, and thus handicapped within the meaning of 29 U.S.C. 706(7)(B)(iii).

It also would seem clear that a handicapped newborn infant who, solely because of his handicap, is denied nourishment or treatment that would be medically beneficial is an "otherwise qualified" handicapped individual who has been "denied the benefits of" and "subjected to discrimination under" the federally assisted program within the meaning of Section 504. This Court stated in *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979), that the "plain meaning" of the term otherwise qualified handicapped individual is "one who is able

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metic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin; and endocrine; or (B) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities." 45 C.F.R. 84.3(j)(2)(i).

[9] HHS regulations define the term "major life activities" to mean "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 45 C.F.R. 84.3(j)(2)(ii). Although newborn infants obviously cannot perform some of these functions, others of those mentioned (*e.g.*, seeing, hearing, breathing and learning) are capable of being performed by infants. Moreover, this listing expressly is not exclusive (it refers to functions "such as" those listed), and it therefore readily embraces any functions or activities that are comparably "major" in the life of an infant. In *University Hospital*, for example, the court of appeals noted that Baby Jane Doe's rectal, bladder, leg, and sensory functions were all then presently impaired and that, with or without corrective surgery, she would experience severe mental retardation throughout her life (App., *infra*, 27a).

to meet all of a program's requirements in spite of his handicap." In *Davis* a deaf student was, because of her handicap, not qualified for admission to nursing school because she could not meet some of the educational program's basic physical requirements. Obviously, one need not possess any special qualifications to benefit from receiving nourishment. Similarly, in the context of the furnishing of health services, there ordinarily are no qualifications that a patient must meet other than to have the ability, in spite of his handicap, to benefit from medical treatment.[10] Accordingly, if an infant's handicapping condition would not prevent him from benefitting from, for example, corrective surgery, he must be considered "otherwise qualified." That is the principle HHS applied in adopting the regulations and interpretative guidelines at issue here.[11]

On this understanding, if a federally assisted hospital refused to furnish an infant who has a handicap (*e.g.*, Down's Syndrome) with treatment that would be medically beneficial (*e.g.*, surgery to remove an intestinal blockage (see note 2, *supra*)) and that would be performed for a child who is not handicapped, the infant quite clearly has, "solely by reason of his handicap," been "denied the benefits of" and been "subjected to discrimination under" the federally assisted program. Thus, contrary to the court of appeals' conclusion, the regulations and interpretative guidelines respondents challenge are firmly supported by the plain language of Section 504.[12]

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[10] See 45 C.F.R. 84.3(k)(4) (as regards health and other services, a qualified handicapped person is one "who meets the essential eligibility requirements for the receipt of such services"); 45 C.F.R. Pt. 84, App. A para. 5.

[11] "If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is 'otherwise qualified' to receive that treatment or service, and it may not be denied solely on the basis of the handicap." 49 Fed. Reg. 1636 (1984); see also *id.* at 1630.

[12] Section 504 prohibits discrimination only in a "program or activity receiving Federal financial assistance," but no question is

The majority in *University Hospital* attempted to avoid this conclusion by reasoning that the phrase "otherwise qualified" is geared toward relatively "static" pro-

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presented here regarding this aspect of the coverage of Section 504. Compare *Consolidated Rail Corp.* v. *Darrone*, slip op. 11-12; *North Haven Board of Education* v. *Bell*, 456 U.S. at 540. The district court in *University Hospital* held that the hospital program's receipt of payments for the furnishing of medical treatment under the Medicaid and Medicare Programs, 42 U.S.C. 1395 *et seq.*, 1396 *et seq.*, constituted the receipt of "Federal financial assistance" that triggered the application of Section 504, whether or not Baby Jane Doe herself was a beneficiary under the Medicaid Program. 575 F. Supp. at 612-613. Compare *Grove City College* v. *Bell*, No. 82-792 (Feb. 28, 1984), slip op. 15 n.21. This holding is consistent with HHS's longstanding position (see 45 C.F.R. Pt. 84, App. A paras. 1, 2) and with the holding of the only court of appeals to have extensively considered the question. See *United States* v. *Baylor University Medical Center*, 736 F.2d 1039, 1042-1049 (5th Cir. 1984), cert. denied, No. 84-525 (Jan. 21, 1985).

However, the court of appeals in *University Hospital* declined to resolve this question. It assumed for purposes of the decision that the hospital's actions pertaining to Baby Jane Doe *were* under a program or activity receiving federal financial assistance by virtue of the hospital's receipt of Medicare and Medicaid funds (App., *infra*, 16a-18a), but it held that Section 504 did not in any event address the question of discrimination in the medical treatment of handicapped infants (*id.* at 18a-41a). The district court and court of appeals in the instant case entered judgment in favor of respondents on the basis of that holding in *University Hospital* (*id.* at 2a, 49a), and they therefore likewise had no occasion to consider whether a hospital's receipt of Medicare and Medicaid payments made Section 504 applicable to the furnishing of medical services to patients in covered programs.

Moreover, the regulations that respondents challenge in this suit (45 C.F.R. 84.55 and Pt. 84, App. C) are quite general and do not even address the question of what constitutes a program or activity receiving federal financial assistance for purposes of Section 504. That question therefore can be addressed only in the context of the application of Section 504 and the regulations and guidelines at issue here to a particular hospital. In such a case, it would be appropriate to consider not only the particular hospital's receipt of Medicare and Medicaid funds, but also other forms of federal financial assistance, such as Hill-Burton and other construction funds. See, *e.g.*, 42 U.S.C. 291 *et seq.*

grams or activities such as education, employment, and transportation systems, and cannot be applied in the comparatively "fluid" context of medical treatment decisions without "distorting its plain meaning" (App., *infra*, 30a). But it is the majority below that is distorting the plain meaning of Section 504, because the supposed distinction between "static" and "fluid" contexts finds no support whatever in the statutory language. Section 504 broadly prohibits discrimination in "*any* program or activity receiving Federal financial assistance" ((emphasis added); see *Consolidated Rail Corp.* v. *Darrone*, slip op. 7), a phrase that clearly encompasses the furnishing of health services. See S. Rep. 93-1297, 93d Cong., 2d Sess. 38 (1974); 45 C.F.R. 84.3(h), 84.52.

By its use of the term "fluid," the majority apparently meant that a handicapped infant's need for a particular course of treatment may vary with changes in the child's physical condition. Where such fluidity is present, it may appropriately inform the range of reasonable medical alternatives and thereby support additional deference to a physician's professional medical judgment. But the fact that some physical conditions may fluctuate does not support a wholesale exemption from Section 504 for *all* decisions relating to medical treatment. There was, for example, nothing "fluid" about the Bloomington Baby Doe's need for corrective esophageal surgery to enable him to receive nourishment.[13] By the same token, programs and activities other than the furnishing of health services are not necessarily "static," as the majority in *University Hospital* seemed to believe. For example, in a federally assisted educational program, decisions that

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[13] Moreover, the potentially "fluid" nature of a patient's condition would not immunize a medical treatment decision from scrutiny to determine whether it was based on the race of the patient, in violation of Title VI. Because Section 504 was patterned after Title VI (see pages 19-20, *infra*), there is no reason to believe that Congress intended to confer such a blanket immunity under Section 504 either.

affect a handicapped child are made every day, and adjustments might have to be made in that program to take into account fluctuations in the child's physical or mental condition. In short, the distinction the majority posited finds no basis in the statutory language, the policies of Section 504, or common sense.

b. The legislative history of Section 504 also fully supports the validity of the regulations. The legislative history of Section 504 as originally enacted is relatively sparse, but it describes the Section in broad terms that contain no suggestion that Congress intended to create the exception fashioned by the court of appeals.[14] The breadth of Section 504 is further stressed in S. Rep. 93-1297, 93d Cong., 2d Sess. (1974), which was issued in connection with the 1974 addition of the definition of the term "handicapped individual" in 29 U.S.C. 706 (7)(B) and upon which this Court repeatedly has relied as an authoritative exposition of the congressional intent underlying Section 504.[15] That report states that Section 504 "was enacted to prevent discrimination against all handicapped individuals * * * in relation to Federal assistance in employment, housing, transportation, education, *health services*, or any other Federally-assisted programs" and "constitutes the establishment of a *broad government policy* that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap." S. Rep. 93-1297, *supra*, at 38-39 (emphasis added).

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[14] See, *e.g.*, S. Rep. 93-48, 93d Cong., 1st Sess. 55, 80 (1973); S. Rep. 93-318, 93d Cong., 1st Sess. 50, 70 (1973); 118 Cong. Rec. 30681 (1972) (remarks of Sen. Randolph); *id.* at 32310 (remarks of Sen. Humphrey); 119 Cong. Rec. 5862 (1973) (remarks of Sen. Cranston).

[15] See *Southeastern Community College* v. *Davis*, 442 U.S. at 406 n.6; *Community Television* v. *Gottfried*, 459 U.S. 498, 509 (1983); *Consolidated Rail Corp.* v. *Darrone*, slip op. 10 n.15; *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), slip op. 5 n.7, 16 n.24; see also *id.* at 18-19 & n.27.

In addition, the Senate Report underscores what is in any event evident from the language of Section 504: that it is patterned directly after Title VI of the Civil Rights Act of 1964 (see S. Rep. 93-1297, *supra*, at 39) and that Congress therefore concluded that discrimination because of handicap should be viewed as "similar to discrimination because of race" (*id.* at 38). See *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), slip op. 5 & n.7, 7-8 n.13; *Consolidated Rail Corp* v. *Darrone*, slip op. 5-6, 10 n.16; *Community Television* v *Gottfried*, 459 U.S. at 509. This congressionally mandated analogy to racial discrimination, at least in the context of intentional discrimination (compare *Alexander* v. *Choate*, slip op. 6-11), further reinforces the validity of the regulations at issue here. The Secretary's interpretative guidelines expressly provide that reasonable medical judgments will be respected. 45 C.F.R. Pt. 84, App. C para. (a)(3). But as Judge Winter expalined in his dissent in *University Hospital* (App., *infra*, 44a), not every decision by a hospital that happens to relate to the furnishing of medical treatment is perforce a bona fide medical judgment that is automatically immune from scrutiny under the antidiscrimination laws. Surely, for example, a federally assisted hospital would not be free under Title VI to decline to perform surgery to remove an intestinal obstruction in an infant solely because of his race. Although such a decision would relate to medical treatment, it would not be a bona fide medical judgment. It is equally unlawful under Section 504 for the hospital to decline to perform the same surgery on an infant solely because of his handicap (*e.g.*, Down's Syndrome). Moreover, just as a hospital could not, under Title VI, decline solely because of the child's race to take appropriate steps to override a parental withholding of consent to needed treatment, a hospital cannot, under Section 504, decline to do so solely because of the child's handicap.

The panel majority in *University Hospital* believed that the analogy to racial discrimination "breaks down," reasoning that "[w]here the handicapping condition is

related to the condition[s] to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'" (App., *infra*, 30a-31a). Even assuming this observation were correct as an analytical matter (but see note 17, *infra*), it says nothing about those instances in which the handicapping condition is *not* necessarily related to the impairment to be treated. In the widely publicized Bloomington Baby Doe case, a decision was made to forego routine surgery on an intestinal blockage of a newborn child with Down's Syndrome because such treatment would not cure the child's mental retardation.[16] The child starved to death. The intestinal blockage plainly was separable from any retardation associated with Down's Syndrome that would have remained after the corrective surgery, and if the infant had not been handicapped, the hospital surely would have taken steps to provide the routine corrective surgery. There is no difficulty in determining that such a decision is "discriminatory." [17]

The court of appeals in *University Hospital* also drew a negative inference from the fact that medical treatment decisions were not specifically mentioned in the legislative history of Section 504 (App., *infra*, 31a-35a).

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[16] *In re Infant Doe*, No. GU 8204-004A (Apr. 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind. Cir. Ct. May 27, 1982) (case mooted by child's death). There are other documented instances of children with Down's Syndrome being denied routine corrective surgery for intestinal blockages. See 48 Fed. Reg. 30847 (1983).

[17] As the Secretary explained when she promulgated the regulations at issue here, the same analytical framework applies where the handicapping condition and the condition to be treated are the same. In such a case, the "handicap" is the physical or mental impairment that would remain *after* completion of the treatment involved. The Secretary acknowledged that application of the analytical framework may be more difficult in such circumstances because of the interrelatedness of the medical considerations. 49 Fed. Reg. 1637 (1984). But the existence of some difficult cases scarcely justifies the wholesale exclusion fashioned by the court of appeals for *all* medical treatment decisions.

But Congress's failure to advert expressly to a particular application that the words and purpose of the statute clearly embrace does not negate that application. See, *e.g.*, *Jefferson County Pharmaceutical Ass'n* v. *Abbott Laboratories*, 460 U.S. 150, 159 n.18 (1983), and cases cited. See also *United States* v. *Weber Aircraft Corp.*, No. 82-1616 (Mar. 20, 1984), slip op. 8, 9-11. That is especially so where, as here, Congress has deliberately enacted a sweeping policy covering a broad range of programs and left to the agencies concerned the responsibility to elaborate upon that policy in particular contexts. See pages 21-22, *infra*.

Equally without merit is the court of appeals' reliance on what it believed was Congress's exclusive concern in the legislative history with access by handicapped persons to federally assisted programs (App., *infra*, 33a-35a). Section 504 on its face addresses not only the matter of access (by providing that a handicapped person may not "be excluded from the participation in" the program or activity); it further provides that a person may not be "denied the benefits of" or be "subjected to discrimination under" the program, even if he does have some measure of access to it. In other words, Section 504 requires "evenhanded treatment" of handicapped individuals. *Alexander* v. *Choate*, slip op. 16. Section 504 should be " 'accord[ed] * * * a sweep as broad as its language,' " and courts should not "read into [the statute] a limitation [*i.e.*, an exclusion for medical treatment decisions] not apparent on its face." *Grove City College* v. *Bell*, No. 82-792 (Feb. 28, 1984), slip op. 8, quoting *North Haven Board of Education* v. *Bell*, 456 U.S. at 521.

c. The court of appeals also failed to accord any deference to the Secretary's regulations and guidelines implementing Section 504 (App., *infra*, 25a). Its decision in this respect is contrary to the congressional intent that the Secretary promulgate such regulations (S. Rep. 93-1297, *supra*, at 39-40) and to this Court's recognition

that "these regulations [are] an important source of guidance on the meaning of § 504." *Alexander* v. *Choate*, slip op. 16 n.24; see also *Southeastern Community College* v. *Davis*, 442 U.S. at 413. The regulations promulgated by the Secretary in 1977 expressly provide that Section 504 applies to federally assisted programs for the furnishing of health services (45 C.F.R. 84.4, 84.52, 84.53), and the Secretary made clear at the time of promulgation that medical treatment decisions are covered.[18] The original regulations did not specifically mention the subcategory of treatment decisions involving handicapped newborn infants, but this obviously does not mean that it or any other subcategory was implicitly excluded from coverage.

The regulations promulgated in 1984, at issue here, were intended simply to provide further guidance regarding the application of the general principles of nondiscrimination in this particular setting. Congress intended that the Secretary would have "substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*, slip op. 16 n.24, citing S. Rep. 93-1297, *supra*, at 40-41, 56. See also *id.* at 19-20 n.32. This is a continuing responsibility of the Secretary that may require her to respond to reports of apparent discrimination, such as the Bloomington Baby Doe case that led to the regulations at issue here. See *Southeastern Community College* v. *Davis*, 442 U.S. at 413 (emphasis added) ("Identification of those instances where a refusal to accommodate the needs of a disabled person amounts to discrimination against the handicapped

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[18] See 45 C.F.R. Pt. 84, App. A para. 36:

> [A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

continues to be an important responsibility of HEW."); *Community Television* v. *Gottfried*, 459 U.S. at 512; cf. *Lau* v. *Nichols*, 414 U.S. 563 (1974); *Guardians Ass'n* v. *Civil Service Comm'n of New York City*, 463 U.S. 582 (1983).

The court of appeals believed that the Secretary had disclaimed any authority with respect to medical treatment decisions when the present Section 504 regulations were proposed in 1976, and it discounted the Secretary's current view on that ground (App., *infra*, 18a-19a, 25a). The court of appeals was wrong. All that the Secretary determined in 1976 was that Section 504 did not authorize regulations "concerning adequate and appropriate psychiatric care or safe and humane living conditions for persons institutionalized because of handicap or concerning payment of fair compensation to patients who perform work." 41 Fed. Reg. 29548, 29559 (1976). In other words, Section 504 was not understood to confer on institutionalized persons a right to safe conditions or to treatment.[19] This conclusion of course was consistent with the fact that Section 504 is concerned only with discrimination in the *relative* treatment of handicapped and nonhandicapped persons and does not confer any *absolute* right to receive particular services or benefits under federally assisted programs. The Secretary did not suggest that Section 504 is inapplicable even where there *is* discrimination between the handicapped and nonhandicapped with respect to the furnishing of particular medical services.

When the Secretary promulgated the instant regulations in 1984, she distinguished the comments during the rulemaking proceedings in 1976 on the ground just discussed (49 Fed. Reg. 1636 (1984)), and that interpretation of the Department's prior action is itself entitled to substantial deference. *Udall* v. *Tallman*, 380 U.S. 1, 16-

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[19] That distinct question was addressed by this Court as a constitutional matter in *Youngberg* v. *Romeo*, 457 U.S. 307 (1982).

17 (1965). Moreover, the fact that the Secretary was of the view after 1977 that Section 504 *does* apply to the discriminatory withholding of medical treatment from a handicapped infant is demonstrated by the fact that in May 1980, HHS formally resolved a Section 504 complaint against a hospital arising out of the death in 1979 of an infant with Down's Syndrome who had an intestinal blockage. In the compliance agreement, the hospital committed itself to report to the state child protective services agency any cases involving a lack of parental consent to medically indicated treatment for handicapped infants in the same manner as it reports similar cases involving nonhandicapped children. See 48 Fed. Reg. 30847-30848 (1983). Thus, the 1984 regulations the court of appeals invalidated do not reflect a new administrative interpretation of Section 504, much less a reversal of a prior interpretation, as the court of appeals believed. Compare *General Electric Co.* v. *Gilbert*, 429 U.S. 125, 142-143 (1976).

d. The final argument on which the panel majority in *University Hospital* relied was that to require a hospital to seek a court order or take other appropriate steps where the parents have refused to consent to life-saving treatment would constitute an "onerous affirmative action burden" that is impermissible under *Southeastern Community College* v. *Davis* (App., *infra*, 39a). This conclusion was based on a misunderstanding of the Secretary's position, a misinterpretation of *Davis*, and a gross exaggeration of the burden involved. *Davis* held that Section 504 does not obligate a university to make "substantial modifications" in its nursing program to accommodate the needs of a deaf student (442 U.S. at 413). See *Alexander* v. *Choate*, slip op. 13 n.20. It has been the Secretary's consistent position—reflected in the resolution of the 1980 complaint, just discussed (see page 23, *supra*)—that Section 504 requires a hospital to initiate steps to override a parental withholding of con-

sent to life-saving treatment for a handicapped child only if the hospital would have done so for a nonhandicapped child. Thus, Section 504 imposes no new "affirmative action" obligation on a hospital; it imposes only the "burden" of nondiscrimination.

Nor can the taking of the necessary steps in such circumstances be viewed as an impermissibly "onerous" burden on the hospital, especially when weighed against the consequences for the child. Virtually all hospitals are prepared to and do take steps to assure treatment when, for example, religious convictions prohibit the parents of a newborn infant from consenting to medical treatment necessary to the child's survival. Nor is there any doubt that most hospitals would not hesitate to take such steps in the case of a parental refusal to consent to a routine procedure, such as a blood transfusion, necessary to save the life of an otherwise normal and healthy child. It ordinarily would not even be necessary for the hospital to assume responsibility for litigation on the question. The hospital often might fulfill its obligation to afford even-handed treatment for a handicapped child simply by notifying the state child protective services agency, which in turn could investigate the matter and seek any necessary court order.

2. As we have explained, the decision of the court of appeals creating an implied exception from the coverage of Section 504 for all medical treatment decisions involving handicapped newborn infants is flatly inconsistent with the text, purposes, and legislative history of the statute and with the Secretary's implementing regulations and guidelines. The court's error is compounded because this case involves a sweeping nationwide injunction that purports to prohibit the Secretary from undertaking *any* investigation or enforcement action with respect to *any* treatment decision involving an impaired newborn infant in *any* federally assisted program (App., *infra*, 52a). The court below therefore has effectively barred any federal role whatever under Section 504—even of an oversight nature—with regard to the withholding of medi-

cally beneficial treatment from handicapped infants,[20] despite the receipt by hospitals in this country of billions of dollars annually in federal financial assistance under the Medicare and Medicaid Program alone.[21]

As HHS's study of this matter demonstrates (see 48 Fed. Reg. 30847-30848 (1983)), refusals to treat even moderately handicapped newborns has been more than just a rare occurrence. The protection that the Secretary's regulations afford these infants is significant, and the absence of such protection may, in some cases, be life-threatening. See 49 Fed. Reg. 1649 (1984). For this reason, and in light of the nationwide impact of the decision below and the resulting absence of a potential for a circuit conflict that might make the issue ripe for review at a later date, the court of appeals' erroneous invalidation of the entire regulatory program should not be permitted to stand.[22]

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[20] The *University Hospital* case underscores this point. HHS had not determined in that case that a violation of Section 504 had occurred as a result of the withholding of surgery from Baby Jane Doe. HHS required access to the relevant documents to evaluate the actions of hospital personnel. The court of appeals held, however, that HHS, which administered the substantial payments the hospital received, could not even obtain the information necessary to assess the situation.

[21] In fiscal year 1983, in excess of $38 billion was expended under Part A of the Medicare Program, which principally covers hospital services (*1984 Annual Report of the Board of Trustees of the Federal Hospital Insurance Trust Fund*, H.R. Doc. 98-199, 98th Cong., 2d Sess. 15 (1984)), and in excess of $32 billion was expended under the Medicaid Program, which covers both inpatient and outpatient services (Office of Financial and Actuarial Analysis, Health Care Financing Administration, Department of Health and Human Services, *Annual Statistical Report No. 2082* (1984)).

[22] On October 9, 1984, Congress passed amendments to the Child Abuse Prevention and Treatment Act (42 U.S.C. 5101 *et seq.*). See Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* In those amendments Congress required that a state child protective services agency, in order to be eligible for federal grants under that Act, must establish procedures for receiving and responding to reports "of medical neglect

Moreover, the court of appeals' view that Section 504 does not apply in what it termed the "fluid" context of medical treatment decisions is not logically limited to infants with life-threatening or other severe conditions, or even to infants. It therefore calls into question the applicability of Section 504 to medical treatment decisions affecting handicapped individuals generally. In addition, the court of appeals' suggestion that Section 504 is limited only to matters of access by the handicapped, or is confined by reference to the particular examples of dis-

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(including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions) * * *" (§ 122, 98 Stat. 1752). (Similar state procedures are required under the Secretary's Section 504 regulations at issue here. See 45 C.F.R. 84.55(c).).

These new amendments do not, either practically or legally, obviate the need for review in this case. The amendments only require the state child protective agency to have in place procedures for receiving and investigating possible cases of failure to treat handicapped infants. The role of HHS under the amendments is only to insure that the state procedures are in place and are followed by the state agency. The amendments, unlike Section 504, place no independent federal duty on hospitals and other providers of services with regard to the treatment of handicapped infants. The application of Section 504 in this setting therefore is critical to ensure that hospitals also have an obligation under federal law to assure that handicapped infants are treated in an evenhanded manner and to assure, where necessary, the opportunity for direct investigation and enforcement by HHS regarding particular cases of discriminatory withholding of medically indicated treatment from handicapped infants.

Moreover, Section 127(a) of the Child Abuse Amendments of 1984 (98 Stat. 1754) states that "[n]o provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973." See also 130 Cong. Rec. S11699 (daily ed. Sep. 21, 1984) (letter of Sen. Hatch, et al.). The new legislation therefore does not affect the legal or practical importance of this case, which will effectively establish the applicability of Section 504 to hospital treatment decisions. See also 49 Fed. Reg. 48165-48166 (Dec. 10, 1984) (discussing interaction between Child Abuse and Treatment Act Amendments and Section 504).

criminatory treatment that were expressly mentioned in the legislative history, could adversely affect the enforcement of Section 504 outside of the context of medical treatment. Finally, the court's analysis of these issues could impede enforcement of other antidiscrimination statutes that are worded identically to Section 504, such as Title VI of the Civil Rights Act of 1964, regarding discrimination on the basis of race in the furnishing of medical services and other matters. Review by this Court therefore is plainly warranted.

CONCLUSION

The petition for a writ of certiorari should be granted.

Respectfully submitted.

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MARCH 1985

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* The Solicitor General is disqualified in this case.

APPENDIX A

UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

At a stated Term of the United States Court of Appeals for the Second Circuit, held at the United States Courthouse in the City of New York, on the 27th day of December one thousand nine hundred and eighty-four.

Present: HONORABLE JON O. NEWMAN,
HONORABLE GEORGE C. PRATT,
HONORABLE JOHN W. PECK,*
Circuit Judges.

84-6211

AMERICAN HOSPITAL ASSOCIATION, ET AL.,
PLAINTIFF-APPELLEES

v.

MARGARET M. HECKLER, Secretary,
United States Department of Health and
Human Services, DEFENDANT-APPELLANT

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* Of the United States Court of Appeals for the Sixth Circuit, sitting by designation.

84-6213

AMERICAN MEDICAL ASSOCIATION, ET AL.,
PLAINTIFFS-APPELLEES

v.

MARGARET M. HECKLER, Secretary,
Department of Health and Human Services,
DEFENDANT-APPELLANT

[Filed Dec. 27, 1984]

ORDER

The appellant, the Secretary of Health and Human Services, has moved for summary disposition, without briefing or oral argument, of her appeal from a judgment of the District Court for the Southern District of New York (Charles L. Brieant, Judge). The judgment declared invalid and enjoined enforcement of regulations, purportedly promulgated pursuant to section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982), concerning medical treatment of handicapped infants. The Secretary acknowledges that Judge Brieant's decision and this panel's affirmance of it are compelled by this Court's prior decision in *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984).

Having reviewed the briefs, we agree that summary disposition without oral argument is appropri-

ate. Accordingly, the judgment of the District Court is affirmed.

/s/ John O. Newman

/s/ George C. Pratt

/s/ John W. Peck (per J.O.N.)
Circuit Judges

N.B. Since this statement does not constitute a formal opinion of this court and is not uniformly available to all parties, it shall not be reported, cited or otherwise used in unrelated cases before this or any other court.

APPENDIX B

UNITED STATES COURT OF APPEALS
FOR THE SECOND CIRCUIT

August Term 1983

Docket No. 83-6343

UNITED STATES OF AMERICA, PLAINTIFF-APPELLANT

—against—

UNIVERSITY HOSPITAL, STATE UNIVERSITY OF NEW YORK AT STONY BROOK, DEFENDANT-APPELLEE

PARENTS OF BABY JANE DOE,
INTERVENORS-DEFENDANTS-APPELLEES

No. 679

Argued: December 2, 1983

Decided: 2-23-84

Before: WINTER and PRATT, Circuit Judges, and METZNER, District Judge *.

Appeal from a summary judgment entered in the United States District Court for the Eastern District of New York (Leonard D. Wexler, *Judge*), denying the United States Department of Health and Human Services access to certain medical records maintained by defendant University Hospital.

Affirmed. Judge Winter dissents in a separate opinion.

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* Hon. Charles M. Metzner, of the United States District Court for the Southern District of New York, sitting by designation.

PRATT, *Circuit Judge*:

This expedited appeal presents the question whether Section 504 of the Rehabilitation Act of 1973, as amended, 29 U.S.C. § 794 (Supp. V 1981), and one of its implementing regulations, 45 C.F.R. § 84.61 (1982) (incorporating 45 C.F.R. § 80.6(c) (1982)), authorize the United States Department of Health and Human Services (HHS) to obtain access to medical records maintained by defendant University Hospital concerning a seriously deformed newborn infant, identified only as Baby Jane Doe, whose parents have refused to consent to certain surgical procedures necessary to prolong the infant's life. The United States District Court for the Eastern District of New York (Leonard D. Wexler, *Judge*) ruled that HHS was not entitled to the records and entered summary judgment in favor of University Hospital. For the reasons set forth below, we affirm.

I.

Baby Jane Doe was born on October 11, 1983 at St. Charles Hospital in Port Jefferson, New York. She was suffering from multiple birth defects, the most serious of which were myelomeningocele, commonly known as spina bifida, a condition in which the spinal cord and membranes that envelop it are exposed; microcephaly, an abnormally small head; and hydrocephalus, a condition characterized by an accumulation of fluid in the cranial vault. In addition, she exhibited a "weak face", which prevents the infant from closing her eyes or making a full suck with her tongue; a malformed brain stem; upper extremity spasticity; and a thumb entirely within her fist.

As a result of the spina bifida, the baby's rectal, bladder, leg, and sensory functions were impaired.

Due to the combination of microcephaly and hydrocephalus, there was an extremely high risk that the child would be so severely retarded that she could never interact with her environment or with other people.

At the direction of the first pediatric neurosurgeon to examine her, the baby was immediately transferred to University Hospital for dual surgery to correct her spina bifida and hydrocephalus. Essentially, this would entail excising a sac of fluid and nerve endings on the spine and closing the opening, and implanting a shunt to relieve pressure caused by fluid build-up in the cranial cavity. The record indicates that these dual, corrective surgical procedures were likely to prolong the infant's life, but would not improve many of her handicapping conditions, including her anticipated mental retardation.

After consulting with several physicians, nurses, religious advisors, a social worker, and members of their family, the parents of the baby decided to forego the corrective surgery. Instead, they opted for a "conservative" medical treatment consisting of good nutrition, the administration of antibiotics, and the dressing of the baby's exposed spinal sac.

Litigation surrounding Baby Jane Doe began on October 16, when A. Lawrence Washburn, Jr., a Vermont attorney unrelated to the child and her family, commenced a proceeding in New York State Supreme Court seeking appointment of a guardian *ad litem* for the child and an order directing University Hospital to perform the corrective surgery. The court appointed William E. Weber as guardian *ad litem* and held an evidentiary hearing on October 19 and 20 to determine whether Baby Jane Doe was "in need of immediate surgical procedures to preserve

her life". Following the hearing, at which University Hospital and the parents of the child were represented, the court concluded that surgery was necessary and ordered that it be performed.

One day later the Appellate Division of the New York Supreme Court reversed the decision of the trial court and dismissed the proceeding. The Appellate Division found that the "concededly concerned and loving parents have made an informed, intelligent, and reasonable determination based upon and supported by responsible medical authority." As the court elaborated:

> The record confirms that the failure to perform the surgery will not place the infant in imminent danger of death, although surgery might significantly reduce the risk of infection. On the other hand, successful results could also be achieved with antibiotic therapy. Further, while the mortality rate is higher where conservative medical treatment is used, in this particular case the surgical procedures also involve a great risk of depriving the infant of what little function remains in her legs, and would also result in recurring urinary tract and possibly kidney infections, skin infections and edemas of the limbs.

Thus, the Appellate Division determined that the parents' decision was in the best interest of the infant and that there was, therefore, no basis for judicial intervention.

On October 28, the New York Court of Appeals affirmed the decision of the Appellate Division, relying on different grounds. Since the petitioner had no direct interest in or relationship to any party and had failed to contact the State Department of Social

Services, which has primary responsibility under New York law for initiating child neglect proceedings, and since the trial court also had failed to seek that department's investigative assistance, the Court of Appeals found "no precedent or authority" for the proceeding. Accordingly, the Court of Appeals ruled that the trial court had abused its discretion by permitting the proceeding to go forward.

While the state court proceedings were still in progress, the federal government entered the picture. On October 19, HHS received a complaint from an unidentified "private citizen" that Baby Jane Doe was being discriminatorily denied medically indicated treatment on the basis of her handicaps. HHS referred the complaint to the New York State Child Protection Services, the state agency specifically responsible for investigating suspected incidents of child abuse, mistreatment, and neglect. On November 7, that agency concluded that there was no cause for state intervention.

Meanwhile, HHS obtained a copy of the record of the state court proceedings, which contained the child's medical records through October 19. The record was forwarded to and personally reviewed by the Surgeon General of the United States, who determined, among other things, that:

> An appropriate determination concerning whether the current care of Infant Jane Doe is within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment, cannot be made without immediate access to, and careful review of, current medical records and other sources of infor-

mation within the possession or control of the hospital.

Beginning on October 22, HHS repeatedly requested University Hospital to make available for inspection all of Baby Jane Doe's medical records since October 19. HHS based its authority to conduct an investigation on section 504 of the Rehabilitation Act, which provides in pertinent part that "[n]o otherwise qualified handicapped individual * * * shall, solely by reason of his handicap, * * * be subjected to discrimination under any program or activity receiving Federal financial assistance * * *". HHS further relied on 45 C.F.R. § 80.6(c), as incorporated by 45 C.F.R. § 84.61, which states:

> (c) *Access to sources of information.* Each recipient [of Federal financial assistance] shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part. * * * Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part. * * *

University Hospital refused to honor HHS's requests, basing its decision in part on the refusal of the parents to release the records and in part on "serious concerns both as to the Department's jurisdiction and the procedures the Department has employed in initiating an inquiry."

The government then brought this action on November 2, alleging that University Hospital had violated section 504 and 45 C.F.R. § 80.6(c) by refusing

to allow HHS access to information concerning the medical care and hospital services being rendered to Baby Jane Doe. After the parents had intervened as defendants, and after the district court had granted the government's request to expedite the proceedings, both the hospital and the parents moved to dismiss the complaint, arguing, among other things, that (1) congress did not intend section 504 to reach decisions regarding health care services provided to infants; (2) section 504 imposes no affirmative treatment obligations on the hospital beyond providing handicapped persons equal access to its facilities, which the hospital had done; (3) medicare and medicaid reimbursements do not constitute "Federal financial assistance" within the meaning of section 504; (4) Baby Jane Doe's medical records were protected from disclosure by both her and her parents' federal constitutional privacy rights; and (5) the failure of the federal government to intervene in the state court proceedings barred the instant action under the doctrine of laches. Among the papers submitted in support of these motions was the entire record of the state court proceedings.

The government cross-moved for summary judgment, contending that HHS was entitled to the requested records because (1) the hospital's neonatal unit was a "recipient" of "Federal financial assistance" in the form of medicaid and (2) under 45 C.F.R. § 80.6(c) any such "recipient" was required to allow HHS access to information necessary to the discharge of the agency's statutory obligation to insure compliance with section 504.

Following oral argument on November 17, during which the government conceded that it had found no evidence of discrimination in the records covering

the period through October 19, the district court ruled that defendants were entitled to summary judgment. The court first rejected defendants' claims that (1) the suit was barred by laches; (2) access to the records was barred by New York's physician-patient evidentiary privilege; and (3) medicare and medicaid do not constitute "Federal financial assistance" within the meaning of section 504. Further, the court ruled that the entire hospital, not just its neonatal unit, was the "program or activity" covered by the statute.

Noting that 45 C.F.R. § 80.6(c) requires recipients of federal funds to provide HHS "access to such records 'as may be pertinent to ascertain compliance with' " section 504, the district court next reasoned that "if a recipient of federal financial assistance is clearly not violating [section 504] by discriminating against handicapped persons, the Department of Health and Human Services may not obtain access to the records of such recipient * * *". The court then turned to what it considered the central question: "whether, from the papers submitted to the Court, it can be clearly determined that the defendant University Hospital has not violated the statute by discriminating against a handicapped person." Emphasizing that the hospital "has at all times been willing to perform the surgical procedures in question", but "lacks the legal right to perform such procedures" in the absence of parental consent, the court concluded that the hospital "failed to perform the surgical procedures in question, not because Baby Jane Doe is handicapped, but because her parents have refused to consent to such procedures." Thus, in the court's view, "the failure of the defendant University Hospital to perform the surgical pro-

cedures cannot possibly be regarded as a violation of the Rehabilitation Act."

In any case, the court went on, "the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child." According to the court, this precluded any possibility of liability on the part of the hospital.

On appeal, the government, supported by various *amici*, argues that the district court erroneously required HHS "to make an advance evidentiary showing on the ultimate issue of unlawful conduct as a condition to securing the very materials necessary to reach a determination on that issue". In any event, the government contends, the district court's finding that no discrimination occurred could only have applied to the period up to October 19. Because "[m]edical decisionmaking is a dynamic process", the government claims that whatever the circumstances before October 19, the possibility remains that changes in the baby's conditions after that date would render the hospital's conduct discriminatory under section 504.

The government's principal argument, however, is that the district court erred in concluding that the parents' refusal to consent to surgery conclusively established the hospital's nondiscrimination and thus insulated the hospital from liability under section 504. In this regard, the government claims, for the first time on appeal, that the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents' decision and compelling surgery was itself a violation of the nondiscrimination requirements of section 504.

Defendants, on the other hand, together with the various *amici* who support their position, not only defend the district court's decision on its own terms, but also argue that section 504 provides no authority for this action, because (1) medicare and medicaid do not constitute "Federal financial assistance" within the meaning of the statute and (2) congress did not intend that section 504 serve as the basis for federal intervention in medical decisionmaking. In addition, defendants renew their argument that access to the records is barred by New York's physician-patient privilege and the federal constitutional privacy rights of Baby Jane Doe and her parents. Finally, defendants argue that in light of the state court proceedings, this court should deny the federal government access to the records as a matter of equity, comity, and federalism.

II.

As a preliminary matter, we briefly address the general standards governing a request by an investigating administrative agency such as HHS for the records of an institution such as University Hospital. An administrative agency is entitled to access to information "not plainly incompetent or irrelevant to any lawful purpose of the [agency] in the discharge of [its] duties". *Endicott Johnson Corp. v. Perkins*, 317 U.S. 501, 509 (1943); *see United States v. Morton Salt Co.*, 338 U.S. 632, 641-43 (1950); *Oklahoma Press Publishing Co. v. Walling*, 327 U.S. 186, 208-14 (1946); *SEC v. Brigadoon Scotch Distributing Co.*, 480 F.2d 1047, 1052-55 (2d Cir. 1973), *cert. denied*, 415 U.S. 915 (1974); *see generally* 1 K. Davis, *Administrative Law Treatise* § 4.1 *et seq.* (2d ed. 1978). "So long as an agency establishes that an investiga-

tion 'will be conducted pursuant to a legitimate purpose, that the inquiry may be relevant to the purpose, that the information sought is not already within [its] possession, and that the administrative steps required * * * have been followed,' no showing of probable cause need be made to the district court unless a statute indicates otherwise." *SEC v. Wall Street Transcript Corp.*, 422 F.2d 1371, 1375 (2d Cir.) (citations omitted), *cert. denied*, 398 U.S. 958 (1970). Thus, if the district court meant what at one point it seemed to say—that the government was required to establish some evidence of unlawful discrimination as a condition to obtaining the requested records—it increased the burdens placed on the government by applicable precedents.

At the same time, however, and closer to the thrust of the district court's decision as we read it, an agency is not entitled to information sought in connection with an investigation that "overreaches the authority Congress has given". *Oklahoma Press Publishing Co. v. Walling*, 327 U.S. at 217. As we recognized in *United States v. Cabrini Medical Center*, 639 F.2d 908, 910 (2d Cir. 1981), a case also involving section 504, there is "no point in permitting the Government to institute an investigation with its attendant inconvenience, expense, and annoyance if there is and can be no authority for undertaking it." These concerns are particularly acute in a case like the one at bar, where the demand for information arguably implicates constitutionally protected rights, *cf. Carey v. Population Services International*, 431 U.S. 678, 684-85 (1977); *Whalen v. Roe*, 429 U.S. 589, 598-604 (1977); *Roe v. Wade*, 410 U.S. 113, 152-53 (1973); *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965); *compare Pierce v. Society of Sisters*, 268 U.S. 510,

535 (1925) *with Prince v. Massachusetts*, 321 U.S. 158, 164-71 (1944), and also represents an unprecedented exercise of the agency's investigative powers. Under these circumstances, it is incumbent upon this court to exercise particular care in assuring itself that the subject matter of the investigation is within the agency's statutory jurisdiction. *Federal Election Commission v. Machinists Non-Partisan Political League*, 655 F.2d 380, 385-90 (D.C. Cir.), *cert. denied*, 454 U.S. 897 (1981); *Federal Election Commission v. Florida For Kennedy Committee*, 681 F.2d 1281, 1283-86 (11th Cir. 1982).

Thus, while the philosophical, social, and ethical implications of this case may be far-reaching, the precise issue presented for our review is one of statutory construction: Did congress intend section 504 to reach the conduct HHS seeks to investigate? If the investigation is within the scope of section 504, then HHS is entitled to access to Baby Jane Doe's medical records (unless they are protected from disclosure by some statutory or constitutional provision). On the other hand, if the investigation is beyond the scope of section 504, then the district court properly denied access.

III.

To focus more sharply on this central issue, it is first necessary to examine the theory upon which the government predicates its request for the records under section 504. The theory rests on two premises. First, the government draws a distinction between decisionmaking based on a "bona fide medical judgment", which without definition it concedes to be beyond the reach of section 504, and decisionmaking based solely on an individual's handicap, which it argues is covered by section 504. Second, the government identifies Baby Jane Doe's microcephaly, which

the record indicates will result in severe mental retardation, as the handicapping condition. From these premises, the government reasons that if a newborn infant suffering from spina bifida and hydrocephalus, but not microcephaly, would receive treatment or services that differ from those provided to an infant suffering from all three defects, or alternatively, if the hospital would seek a state court order compelling surgery in the former case, but not in the latter, then a violation of section 504 would have been established. Without the requested records, the government concludes, it is impossible to determine whether any such unlawful discrimination has occurred here, at least after October 19.

A.

In evaluating whether this theory entitles the government to the requested records, we initially assume, without deciding, that the district judge properly determined both that the hospital was a recipient of "Federal financial assistance" within the meaning of the statute, and that the "program or activity" to which the statute applies, if at all, is the entire hospital. Were we forced to confront these unsettled questions, *see United States v. Baylor University Medical Center*, 711 F.2d 38, 40 (5th Cir. 1983), *staying* 564 F. Supp. 1495 (N.D. Tex 1983) ("[w]hether Medicare and Medicaid payments constitute federal financial assistance within the meaning of the Rehabilitation Act is a serious legal question that could have a broad impact upon federal/state relations"); *Grove City College v. Bell*, 687 F.2d 684, 700 (3d Cir. 1982) (under the "program or activity" limitation of Title IX of the Education Amendments of 1972, "[w]here the Federal government furnishes indirect or non-earmarked aid to an institution,

* * * the institution itself must be the 'program' "), *cert. granted*, 103 S.Ct. 1181 (1983), *argued* Nov. 29, 1983, *see* 52 U.S.L.W. 3433 (U.S. Dec. 6, 1983), summary judgment could not properly be granted in favor of either side at this juncture. Far from being undisputed, many of the material facts bearing on those issues have simply not been developed in the record. For example, the record does not reveal the total amount of federal medicare and medicaid funds the hospital has received, directly or indirectly, or more importantly, how those funds are allocated among the various "programs" or "activities" that the hospital may conduct. Indeed, the record is devoid of evidence even as to how the hospital is organized, either internally or as part of a network of state-affiliated institutions.

In support of its position that the hospital's neonatal intensive care unit is the operative "program or activity" (a position which the district court did not adopt), the government did submit an affidavit of an HHS official asserting that University Hospital "received $5,317,912 (gross) in Medicaid reimbursement from October 1, 1982 to November 7, 1983 for one thousand eight hundred and nineteen (1,819) neo-natal billings. The Federal share of this amount is $2,250,285." However, this affidavit alone hardly affords a sufficient basis upon which to determine as a matter of law how the program-specificity requirement of section 504 should be applied here, particularly in light of the potential inconsistency, raised at oral argument, between the positions taken by the federal government in this case and in the *Grove City College* case currently pending in the Supreme Court. As both the opinion of the Third Circuit in *Grove City College*, 687 F.2d at 688-89 & nn. 6-9, and the brief submitted by the government to the Su-

preme Court in challenging that decision, Brief for Respondents at 3-5, *Grove City College v. Bell*, No. 82-792, aptly illustrate in the closely analogous context of Title IX, the issue of program-specificity cannot be properly analyzed in the abstract, but instead requires a concrete set of facts. The same is true with respect to the issue whether an institution that receives medicare or medicaid reimbursements is a recipient of "Federal financial assistance" within the meaning of section 504. *See Bernard B. v. Blue Cross and Blue Shield of Greater New York*, 528 F. Supp. 125, 132 (S.D.N.Y. 1981), *aff'd*, 679 F.2d 7 (2d Cir. 1982) (per curiam).

Given an understandable desire on both sides to resolve this dispute expeditiously, however, we are reluctant to remand the case to the district court for further factual development on these important issues. In the interest of justice, we shall therefore bypass them and proceed directly to the dispositive question whether, assuming the entire hospital is covered by section 504, the statute authorizes the type of investigation initiated here.

B.

While the question whether section 504 authorizes HHS to investigate medical treatment decisions involving defective newborn infants is technically one of first impression, we do not write on an entirely clean slate. The regulatory history of the statute reveals that the question has already received considerable attention.

In its original notice of intent to issue proposed rules under section 504, published in May 1976, HHS's predecessor, the Department of Health, Education and Welfare (HEW), requested comment on

fifteen "critical issues", *see* 41 Fed. Reg. 29548, including "[w]hether a regulation should contain provisions concerning [institutionalized] patients' rights to receive or refuse treatment * * *". 41 Fed. Reg. 20296 at 20297. Subsequently, in a July 1976 notice of proposed rulemaking, HEW indicated that it had received several comments urging "that the department did *not* have authority to regulate in this area" (emphasis added). 41 Fed. Reg. 29548 at 29559. HEW embraced this position, announcing that "[t]he Secretary is of the opinion that to promulgate rules on these subjects is beyond the authority of section 504." *Id.*

This limited view of the scope of section 504 was reflected in the first set of proposed regulations promulgated by HEW. The applicable provision, the proposed version of 45 C.F.R. § 84.52, emphasized the "[*a*]*vailability of services*" to handicapped persons and required that services be made "accessible" through use of methods such as "making house calls, referring patients, arranging to meet patients in accessible facilities, and modifying facilities." 41 Fed. Reg. at 29567 (emphasis in original).

Notwithstanding comments that its proposed health services regulation "lacks specificity", 42 Fed. Reg. at 22693, in its final section 504 regulations, issued in May 1977, HEW created a general "Health, welfare, and other social services" provision, 45 C.F.R. § 84.52, which emphasizes "the basic requirement of equal opportunity to receive benefits * * *". 45 C.F.R., Part 84, Appendix A, ¶ 36. The agency did, however, also offer more specific guidance on the nature of the nondiscrimination requirement imposed by the regulation:

> One common misconception about the regulation is that it would require specialized hospitals and

other health care providers to treat all handicapped persons. The regulation makes no such requirement. Thus, a burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

It was not until five years later that HHS first took the position that section 504 made it unlawful for hospitals receiving "Federal financial assistance" to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 397 (D.D.C. 1983) (describing the circumstances leading to this shift in agency policy). This new position was reflected in a "notice * * * to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973", dated May 18, 1982 and published on June 16, 1982. 47 Fed. Reg. 26027. In the notice, HHS "recognize[d] that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused." *Id.* Nevertheless, referring to 45 C.F.R. § 84.4(b)(1)(v), which provides that a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person, the notice admonished that:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.

> • Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

Id.

Nearly a year after this notice was published, in March 1983, HHS issued an interim final rule "to meet the exigent needs that can arise when a handicapped infant is discriminatorily denied food or other medical care." 48 Fed. Reg. 9630. This "novel and far-reaching" regulation, *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 397, would have required "each recipient that provides covered health services to infants" to display posters in conspicuous places "in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery" declaring that "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW". 48 Fed. Reg. at 9631, *amending* 45 C.F.R. § 84.61. The interim regulation also established a confidential "Handicapped Infant Hotline", "[a]vailable 24 hours a day", which "[*a*]*ny person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact*" (emphasis in original). *Id.* Further, the regulation stated that the required access to records "shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." *Id.*

The preamble to the interim rule made clear that HHS believed it could conduct immediate investigations and make immediate referrals to the Depart-

ment of Justice for appropriate legal action. 48 Fed. Reg. at 9631. However, without eschewing "a vigorous federal role in enforcing the federal civil rights at issue", it also indicated that "[t]he Secretary intends to rely heavily on the voluntary cooperation of State and local agencies, which are closest to the scene of violations, and which have traditionally played the key role in the investigation of complaints of child abuse and neglect." *Id.* at 9630.

On April 14, 1983, this interim final rule was struck down by the United States District Court for the District of Columbia. *American Academy of Pediatrics v. Heckler, supra.* In a thorough and informative opinion, Judge Gesell held that the regulation failed to satisfy the requirements of the Administrative Procedure Act, 5 U.S.C. § 551 *et seq.* (1982), in two respects. First, since the rulemaking record indicated the regulation was a product of "haste and inexperience", 561 F. Supp. at 400, and that many relevant factors, including the scope of section 504, were not considered, the court ruled that the interim final rule was arbitrary and capricious under 5 U.S.C. § 706(2)(A). As the court explained:

> Government intervention into the difficult medical and human decisions that must be made in the delivery rooms and newborn intensive care units of our hospitals involves a profound change in the manner in which these decisions affecting the quality of life are made. Any intervention by an agency of the Federal Government should obviously reflect caution and sensitivity, given the present absence of a clear congressional directive.

561 F. Supp. at 403.

Second, the court ruled that the regulation was invalid due to the secretary's failure to follow the pro-

cedural requirements of 5 U.S.C. § 553(b) and (d). In this regard, Judge Gesell reasoned that the interim final rule could not properly be viewed as a restatement of preexisting law or policy, as the government had alleged:

> As [HHS's] counsel acknowledged in argument, the regulation is intended, among other things, to change the course of medical decisionmaking in these cases by eliminating the parents' right to refuse to consent to life-sustaining treatment of their defective newborn. Moreover, the regulation provides for an intrusive on-premises enforcement mechanism that can be triggered by a simple anonymous call. Thus it clearly is more than a "clarification or explanation of an existing rule or statute" and affects substantive rights.

561 F. Supp. at 401 (footnote and citation omitted).

Following this decision, on July 5, 1983 HHS published a proposed rule in which the notice requirement was slightly revised, and a provision was added declaring that "* * * each recipient State child protective services agency shall establish and maintain written methods of administration and procedures to assure that the agency utilizes its full authority pursuant to State law to prevent instances of medical neglect of handicapped infants." 48 Fed. Reg. 30846 at 30851. In the appendix to the proposed rule, HHS listed several examples of decisions that would, in its view, constitute violations of section 504. These included:

> (3) Denial of treatment for medically correctable physical anomalies in children born with

> Spina Bifida, when such denial is based on anticipated mental impairment, paralysis, or incontinence of such child, rather than on reasonable medical judgments that treatment would be futile or too unlikely of success given complications in the particular case.

Id. at 30852.

More recently, on January 12, 1984, after oral argument of this appeal, HHS issued its "final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants." 49 Fed. Reg. 1622. These final rules modified the proposed rules in several major respects. *Id.* For example, HHS adopted the recommendation of several commenters that the federal government encourage, but not require, hospitals to establish Infant Care Review Committees "to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases." 45 C.F.R. § 84.55(a), 49 Fed. Reg. 1651; *see id.* at 1623-25. These committees are not, however, designed to be substitutes for mechanisms to enforce section 504. *Id.* at 1624.

Under the final rules, the notice requirement is also significantly modified. Among other things, the final rules require only that the notice be posted

> at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it,

> the notice need not be posted in area(s) where parents of infant patients will see it.

45 C.F.R. § 84.55(b)(2), 49 Fed. Reg. 1651.

In sum, the regulatory history of section 504 is inconclusive. HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW. Notwithstanding HHS's claims to the contrary, *see* 49 Fed. Reg. at 1635, the current view also represents something of a retreat from the interpretation HHS adopted just last year. In determining whether congress intended section 504 to apply to treatment decisions involving defective newborn infants, we therefore lack the benefit of an administering agency's longstanding, consistent interpretation to which we otherwise might have looked for guidance. *See Frank Diehl Farms v. Secretary of Labor*, 696 F.2d 1325, 1329-31 (11th Cir. 1983); *see also American Federation of Government Employees v. Federal Labor Relations Authority*, 712 F.2d 640, 643 n. 17 (D.C. Cir. 1983); *cf. United States v. Clark*, 454 U.S. 555, 565 (1982); *see generally* 2 K. Davis, *Administrative Law Treatise* § 7.14 (2d ed. 1979).

C.

With this unsettled regulatory background in mind, we turn to the statutory language, which is fundamental to any issue of statutory construction. *See North Haven Board of Education v. Bell*, 456 U.S. 512, 520 (1982). Section 504 provides in pertinent part as follows:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be

> denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Under 29 U.S.C. § 706(7)(B), "the term 'handicapped individual' means * * * any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

The initial inquiry is whether Baby Jane Doe is properly considered a "handicapped individual" within the meaning of section 706(7). The issue is not as simple as it first seems. While there can be no question that Baby Jane Doe currently suffers from "physical or mental impairments", *see* 45 C.F.R. § 84.3(j)(2)(i), it is less clear whether these impairments substantially limit "major life activities".

Defendants and some of the *amici* contend that the phrase "major life activities", undefined in the Rehabilitation Act, should be interpreted to exclude newborn infants from the coverage of section 504. In support, they rely on congress's declaration in section 122(a)(1) of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. No. 95-602, 92 Stat. 2984, codified at 29 U.S.C. § 701, that the purpose of the Rehabilitation Act "is to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living." This purpose, they assert, is inapplicable to newborn infants, since: "By definition, such infants cannot be eligible for programs of employment, vocational rehabilitation or training. Indeed, no program of independent living can be seriously comprehended for

any infant, let alone an infant who has a life-threatening disorder."

Further support for the view that section 504 does not apply to newborn infants can be found in the regulations HHS inherited from HEW. Under 45 C.F.R. § 84.3(j)(2)(ii), " 'Major life activities' means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." With or without corrective surgery, Baby Jane Doe's impairments unquestionably will substantially limit some of these functions in the future. However, the same cannot necessarily be said of the present, since newborn infants simply cannot perform many of these representative functions.

Notwithstanding this ambiguity in the phrase "major life activities", we hold that Baby Jane Doe falls within the definition of a "handicapped individual" in section 706(7)(B). The record indicates that Baby Jane Doe's rectal, bladder, leg, and sensory functions are all presently impaired. Further, the record suggests that, with or without corrective surgery, Baby Jane Doe will experience severe mental retardation for however long she lives. Absent any explicit indication in the statute or regulations that "major life activities" should be defined only with reference to adults, under these circumstances it would defy common sense to rule that she is not presently *regarded* as handicapped under section 706(7)(B)(iii).

Moreover, while congress may not have had handicapped children squarely in mind when it first formulated the definition of a "handicapped individual" in section 706(7)(B) in 1974, *see infra*, it has subsequently evinced its intent that such children re-

ceive at least some of the benefits of the Rehabilitation Act. In 1978, as part of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, congress authorized the Director of the Interagency Committee on Handicapped Research to make grants for research into "services for preschool age handicapped children." Pub. L. No. 95-602, § 111, 92 Stat. 2967, codified at 29 U.S.C. § 762(11). The fact that congress recognized the needs of preschool age handicapped children in section 762(11) undercuts defendants' argument that, since the declared purpose of the entire Rehabilitation Act set forth in section 701 focuses on activities available only to adults, the "major life activities" referred to in section 706(7) should be similarly limited.

Having determined that Baby Jane Doe is a "handicapped individual" under section 706(7)(B), we next consider whether she possibly can be considered an "otherwise qualified" handicapped individual or to have been "subjected to discrimination" under section 504. These two issues are intertwined.

The leading cases construing the "otherwise qualified" criterion of section 504 have involved allegedly discriminatory denials of admission to certain educational programs. *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979); *Doe v. New York University*, 666 F.2d 761 (2d Cir. 1981). In that context, this court in *Doe v. New York University* recognized that:

> * * * it is now clear that [the phrase "otherwise qualified handicapped individual"] refers to a person who is qualified *in spite of* her handicap and that an institution is not required to disregard the disabilities of a handicapped applicant,

> provided the handicap is relevant to reasonable qualifications for acceptance, or to make substantial modifications in its reasonable standards or program to accommodate handicapped individuals but may take an applicant's handicap into consideration, along with all other relevant factors, in determining whether she is qualified for admission.

Id. at 775 (emphasis in original). *Cf.* 45 C.F.R. 84.3(k).

Doe establishes that section 504 prohibits discrimination against a handicapped individual only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question. As defendants here point out, however, where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to, the need for services. Defendants thus argue, and with some force, that the "otherwise qualified" criterion of section 504 cannot be meaningfully applied to a medical treatment decision. Similarly, defendants argue that it would be pointless to inquire whether a patient who was affected by a medical treatment decision was, "solely by reason of his handicap, * * * subjected to discrimination".

The government's answer to both these arguments is that Baby Jane Doe can be viewed as suffering from not one, but multiple handicaps. Indeed, the crux of the government's case is that her microcephaly is the operative handicap, and that the requested records are necessary to determine whether she has been discriminated against solely for that reason.

Despite its superficial logic, the government's theory is flawed in at least two respects. First, the government's view of "otherwise qualified" is divorced from

the statutory language. As the mainstream of cases under section 504 exemplifies, the phrase "otherwise qualified" is geared toward relatively static programs or activities such as education, *e.g.*, *Southeastern Community College v. Davis*, 442 U.S. 397; *Doe v. New York University*, 666 F.2d 761, employment, *e.g.*, *Prewitt v. United States Postal Service*, 662 F.2d 292 (5th Cir. 1981); *Simon v. St. Louis County*, 497 F. Supp. 141, *aff'd in part, rev'd in part on other grounds*, 656 F.2d 316 (8th Cir. 1981), *cert. denied*, 102 S.Ct. 1485 (1982), and transportation systems, *e.g.*, *Dopico v. Goldschmidt*, 687 F.2d 644, 652-53 (2d Cir. 1982). As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents. If congress intended section 504 to apply in this manner, it chose strange language indeed. *See American Trucking Associations, Inc. v. United States*, 602 F.2d 444, 449-50 (D.C. Cir.), *cert. denied*, 444 U.S. 991 (1979) (statutory language "should be given its plain, obvious and rational meaning").

Second, in arguing that Baby Jane may have been "subjected to discrimination" the government has taken an oversimplified view of the medical decision-making process. Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily

by the dissent, breaks down. Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment", however that phrase might be defined. Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.

The legislative history, moreover, indicates that congress never contemplated that section 504 would apply to treatment decisions of this nature. The Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355, was a comprehensive legislative package that was considered and passed by congress three times before it was finally signed into law by President Nixon. S. Rep. No. 318, 93d Cong., 1st Sess., *reprinted in* [1973] U.S. Code Cong. & Ad. News 2076, 2086-90. Each version of the legislation approved by congress contained a provision prohibiting discrimination against the handicapped by federal grantees. *Id.* at 2078-82; *see Le Strange v. Consolidated Rail Corp.*, 687 F.2d 767, 772 (3d Cir. 1982), *cert. granted*, 103 S.Ct. 1181 (1983), *argued* Nov. 29, 1983, *see* 52 U.S.L.W. 3393 (U.S. Nov. 22, 1983). However, this provision, which had been closely patterned after Title VI of the Civil Rights Act of 1964 and Title IX of the Education Amendments of 1972, *see* S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* [1974] U.S. Code Cong. & Ad. News 6373, 6390-91, was never a matter of controversy. Consequently, there is little discussion of it in the volumes of legislative history that were generated. *See Le Strange v. Consolidated Rail Corp., supra.*

The senate committee report that introduced the provision simply stated "[t]he bill further proclaims a policy of nondiscrimination against otherwise qualified handicapped individuals with respect to participation in or access to any program which is in receipt of Federal financial assistance." S. Rep. No. 1135, 92d Cong., 2d Sess. 49, *see* 118 Cong. Rec. 32294. Examples of programs that the provision was designed to cover that were identified on the floor of the senate included housing and employment. *See* 119 Cong. Rec. 5882 (remarks of Sen. Cranston).

Interestingly, the only consideration of medical issues that occurred in connection with the 1973 legislation did not involve the nondiscrimination provision that would eventually become section 504. In the first two versions of the legislation, congress had created several categorical programs to benefit target populations including those with end-stage renal disease and those with severe spinal cord injuries. In vetoing each of the first two versions of the Rehabilitation Act, President Nixon took issue with what he perceived to be congress's attempts to extend what was essentially a vocational program into the medical realm. *See* 118 Cong. Rec. 5880 (first veto memorandum); 119 Cong. Rec. 24570 (second veto memorandum). Ultimately, congress was forced to back down, *see* 119 Cong. Rec. 24566 (remarks of Sen. Cranston), and the final version of the 1973 legislation authorized research projects rather than categorical programs to benefit the target populations with which congress was concerned.

Since the primary purpose of the 1973 legislation was to extend and expand the 53-year old federal-state vocational rehabilitation program, it is not surprising that congress initially defined the phrase "handicapped individual" in terms of employment:

> The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services * * *.

Pub. L. No. 93-112, § 7(6), 87 Stat. 355, 361.

However, because "[i]t was clearly the intent of the Congress in adopting section 503 (affirmative action) and section 504 (nondiscrimination) that the term 'handicapped individual' in those sections was not to be narrowly limited to employment (in the case of section 504), nor to the individual's potential benefit from vocational rehabilitation services under titles I and III (in the case of both sections 503 and 504) of the Act", S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* [1974] U.S. Code Cong. & Ad. News 6373, 6388, congress expanded the definition to its current version, focusing on "major life activities", in the Rehabilitation Act Amendments of 1974, Pub. L. No. 93-516, § 111(a), 88 Stat. 1619. As the senate report accompanying the 1974 amendments elaborated:

> Thus, it was not intended that an employer-government contractor should condition its hiring of handicapped individuals under an affirmative action plan on such individuals' having benefitted, or having a reasonable expectation of benefitting, from vocational rehabilitation services. Similarly, a test of discrimination against a handicapped individual under section 504 should not be couched either in terms of whether such individual's disability is a handicap to employment, or whether such individual can reasonably be ex-

pected to benefit, in terms of employment, from vocational rehabilitation services. Such a test is irrelevant to the many forms of potential discrimination covered by section 504.

Section 504 was enacted to prevent discrimination against all handicapped individuals, regardless of their need for, or ability to benefit from, vocational rehabilitation services, in relation to Federal assistance in employment, housing, transportation, education, health services, or any other Federally-aided programs. Examples of handicapped individuals who may suffer discrimination in receipt of Federally-assisted services but who may have been unintentionally excluded from the protection of section 504 by the references to enhanced employability in section 7(6) are as follows: physically or mentally handicapped children who may be denied admission to Federally-supported school systems on the basis of their handicap; handicapped persons who may be denied admission to Federally-assisted nursing homes on the basis of their handicap; those persons whose handicap is so severe that employment is not feasible but who may be denied the benefits of a wide range of Federal programs; and those persons whose vocational rehabilitation is complete but who may nevertheless be discriminated against in certain Federally-assisted activities.

S. Rep. No. 1297, *supra* at 6388-89.

This passage provides the best clue to congressional intent regarding section 504's coverage of "health services". As Judge Gesell noted in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 401:

> The legislative history * * * [on this subject] focuses on discrimination against adults and older children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were representatives of parents or spokesmen for religious beliefs that would be affected heard.

The post-enactment legislative history also indicates both that congress was primarily concerned with affording the handicapped access to federally-funded programs and activities, and that congress never envisioned that HEW (or HHS) would attempt to apply section 504 to treatment decisions. On April 28, 1977, the day the original set of final section 504 regulations were promulgated by HEW, then Secretary Califano sent congress an explanatory letter. After observing that the regulation "calls for dramatic changes in the actions and attitudes of institutions and individuals who are recipients of HEW funds", and "opens a new era of civil rights in America", Secretary Califano stated that "[i]n light of the limited legislative history, I think it especially important that Congress evaluate the regulation, and the implementation process, to ensure that they conform to the will of Congress." (letter reprinted in Hearings Before the Subcommittee on Select Education of the Committee on Education and Labor of the House of Representatives, 95th Cong., 1st Sess. 76 (hereinafter referred to as "Oversight Hearings")).

Thereafter, the House Subcommittee on Select Education conducted oversight hearings on the section 504 regulations in September 1977. During these hearings, the subcommittee heard testimony covering a wide range of topics from witnesses representing the federal government, state governments, education agencies, and organizations serving handicapped people. Throughout the hearings, the issue of program accessibility was a recurrent theme. *See* Oversight Hearings at 1 (remarks of Congressman Brademas) ("Central to the implementation of these regulations must be the realization that what handicapped people want is access to programs"); 36-37 (remarks of Thomas P. Carroll); 246 (remarks of Debbie Kaplan); 248 (remarks of Ralph Hotchkiss); 295, 358-59, 361 (remarks of David S. Tatel).

On the other hand, although several witnesses echoed Secretary Califano's remark that the newly-issued regulations ushered in a "new era" of civil rights for handicapped citizens, *see* Oversight Hearings at 31 (remarks of Thomas P. Carrol); 337 (remarks of David S. Tatel), and another observed that "many are the issues which cry out for resolution", *id.* at 217 (remarks of James Gashel), at no point did any witness even remotely suggest that section 504 could or would be applied to treatment decisions involving defective newborn infants. Instead, those witnesses who addressed the legal, as opposed to the fiscal, issues raised by HEW's section 504 regulations, including the director of HEW's Office of Civil Rights (OCR), David S. Tatel, *see id.* at 290-368, focused on subjects such as OCR's complaint backlog, *id.* at 218-20 (remarks of James Gashel), and whether attorneys' fees should be made available in private enforcement actions. *Id.* at 2125 (remarks of

Frank G. Bower); 245 (remarks of Debbie Kaplan); 257-63 (remarks of Daniel Yohalem).

We are aware, of course, that "[w]here the words and purpose of a statute plainly apply to a particular situation, * * * the fact that the specific application of the statute never occurred to Congress does not bar us from holding that the situation falls within the statute's coverage." *United States v. Jones*, 607 F.2d 269, 273 (9th Cir. 1979), *cert. denied*, 444 U.S. 1085 (1980); *see Affetto v. TRW, Inc.*, 691 F.2d 357, 362 (7th Cir. 1982); *United States v. Bates*, 617 F.2d 585, 587 n. 7 (10th Cir. 1980); *Portland Cement Association v. Ruckelshaus*, 486 F.2d 375, 380 (D.C. Cir. 1973), *cert. denied*, 417 U.S. 921 (1974); *see also Jefferson County Pharmaceutical Association, Inc. v. Abbott Laboratories*, 103 S.Ct. 1011, 1017 n. 18 (citing cases). Here, however, the government's theory not only strains the statutory language but also goes well beyond congress's overriding concern with guaranteeing handicapped individuals access to programs or activities receiving federal financial assistance. Further, the situation in question is dramatically different in kind, not just in degree, from the applications of section 504 discussed in the legislative history. Under these circumstances, the failure of congress to focus on treatment decisions involving defective newborn infants strikes a telling blow to the government's position.

This void in the legislative history is conspicuous for another reason. Prior to the enactment of the Rehabilitation Act, congress had passed a number of measures limiting federal involvement in medical treatment decisions. For example, the very first section of the medicare law, first enacted in 1965, Pub. L. No. 89-97, § 102(a), 79 Stat. 291, codified at 42

U.S.C. § 1395, ironically one of the laws under which the government purports to exercise jurisdiction in this case, provides that "[n]othing in this subchapter shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided * * *". Similarly, when it enacted the Professional Standards Review Organization (PSRO) provisions of the Social Security Act in 1972, Pub. L. No. 92-603, § 249F (b), 86 Stat. 1429, codified at 42 U.S.C. § 1320c *et seq.*, congress reiterated its view that determinations regarding the quality and appropriateness of medical treatment should not be undertaken by federal officials. *See* S. Rep. No. 1230, 92nd Cong., 2d Sess. 256-58 (1972); *see also Public Citizen Health Research Group v. HEW*, 668 F.2d 537, 542 (D.C. Cir. 1981).

In view of this consistent congressional policy against the involvement of federal personnel in medical treatment decisions, we cannot presume that congress intended to repeal its earlier announcements in the absence of clear evidence of congressional intent to do so. *See Tennessee Valley Authority v. Hill*, 437 U.S. 153, 189-93 (1978) (citing cases). As has already been seen there is no such clear expression of congressional intent in either the language or legislative history of section 504.

Along the same lines, we cannot presume that by enacting section 504, congress intended the federal government to enter the field of child care, which, as HHS has recently acknowledged, has traditionally been occupied by the states. *See* 49 Fed. Reg. 1626-27, 1629-31; 48 Fed. Reg. 9630. Had congress intended to displace state police power functions, it surely would have made that intention explicit.

Finally, case law construing section 504, while not directly on point, also suggests that the government's new interpretation of the statute exceeds the authority conferred by congress. In *Southeastern Community College v. Davis*, 442 U.S. 397 (1979), the Supreme Court emphasized that "[t]he language and structure of the Rehabilitation Act of 1973 reflect the recognition by Congress of the distinction between the evenhanded treatment of qualified handicapped persons and affirmative efforts to overcome the disabilities caused by handicaps." *Id.* at 410. The Court concluded that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." *Id.* at 411. *See American Public Transit Association v. Lewis*, 655 F.2d 1272 (D.C. Cir. 1981), *cf. Dopico v. Goldschmidt*, 687 F.2d 644 (2d Cir. 1982).

In the present case, Baby Jane Doe has been treated in an evenhanded maner at least to the extent that the hospital has always been and remains willing to perform the dual, corrective surgeries if her parents would consent. Requiring the hospital either to undertake surgery notwithstanding the parents' decision or alternatively, to petition the state court to override the parents' decision, would impose a particularly onerous affirmative action burden upon the hospital. *Cf. American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 402 ("section 504 was never intended by Congress to be applied blindly and without any consideration of the burdens and intrusions that might result").

IV.

We have been called upon on this appeal "to determine the applicability of a statute where the language

of the statute does not make crystal clear its intended scope." *Allen v. State Board of Elections*, 393 U.S. 544, 570 (1969). As the Supreme Court stated in *Allen*, "[i]n all such cases we are compelled to resort to the legislative history to determine whether, in light of the articulated purposes of the legislation, Congress intended that the statute apply to the particular case[] in question." *Id*; *see Montana Power Co. v. Federal Power Commission*, 445 F.2d 739, 746 (D.C. Cir. 1970) (*en banc*), *cert. denied*, 400 U.S. 1013 (1971). Our review of the legislative history has shown that congress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants when the statute was enacted in 1973, when it was amended in 1974, or at any subsequent time. Further, neither the articulated purposes of the statute, which concern access and admission to federally-funded programs and activities for otherwise qualified handicapped individuals, nor any fair and reasonable projections of those purposes, *see Montana Power Co. v. Federal Power Commission*, *supra*, nor the applicable case law interpreting the statute, support the far-reaching position advanced by the government in this case.

"[G]iven the present absence of a clear congressional directive", *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 403, we agree with Judge Gesell that "[a]ny intervention by an agency of the Federal Government should obviously reflect caution and sensitivity". *Id.* We go one step further, however, and hold that under these circumstances it is congress, rather than an executive agency, that must weigh the competing interests at stake in this context in the first instance. Until congress has spoken, it

would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.

The judgment of the district court is therefore affirmed.

WINTER, *Circuit Judge, dissenting*:

Since I believe that Section 504 applies to the provision of medical services to handicapped infants, I respectfully dissent. I would reverse and remand for further consideration of whether the kinds of federal financial assistance received by the defendant hospital subject the hospital to the commands of Section 504 in the case of the infant in question.

I

Section 504 provides that

> [n]o otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

29 U.S.C. § 794. It thus states with as much clarity as is reasonably possible that in some circumstances recipients of federal financial assistance may not differentiate between individuals on grounds that one or more is handicapped. The only ambiguity relevant to the present case, I respectfully suggest, is whether the hospital is such a recipient with regard to its obligations to Baby Jane Doe and not whether Section 504 includes the provision of medical services to handicapped infants.

Although modern courts frequently rely upon legislative history to reach results at odds with the seemingly plain language of a statute, only the most compelling reasons should induce a court to override statutory language because the legislative history is silent on a particular point. Such compelling circumstances might exist in the present case if Congress

had no reason to address the questions at hand when it enacted Section 504. It hardly needs stating that the underlying issues brim with political and moral controversy and portend to extend the hand of the federal government into matters traditionally governed by an interaction of parental judgment and state authority. Were I able to conclude that Congress had no reason to address these issues in its consideration of Section 504, I would concur with the majority on the grounds that specific consideration by the Congress of this political and moral minefield would be appropriate before applying the statute as written.

However, such a conclusion is untenable since Section 504 is no first step into a hitherto uncharted legal wilderness. As the Senate Report stated:

> Section 504 was patterned after, and is almost identical to, the antidiscrimination language of section 601 of the Civil Rights Act of 1964, 42 U.S.C. 2000d-1 (relating to race, color, or national origin), and section 901 of the Education Amendments of 1972, 42 U.S.C. 1683 (relating to sex). The section therefore constitutes the establishment of a broad government policy that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap.

S. Rep. No. 1297, 93d Cong., 2d Sess., *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6390. Section 504 was thus enacted against a background of well understood law which was explici ly designated as a guide to interpretation. Congress was persuaded that a handicapped condition is analogous to race and that, so far as the administration of federal fi-

nancial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race.

Once Section 504's legislative heritage is acknowledged, the "void" in the legislative history is eliminated and the many issues raised by defendants with regard to medical decisions, parental judgments and state authority simply evaporate. The government has never taken the position that it is entitled to override a medical judgment. Its position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment. While the majority professes uncertainty as to what that means, application of the analogy to race eliminates all doubt. A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. Finally, once the legislative analogy to race is acknowledged, the intrusion on state authority becomes insignificant.

The logic of the government's position on these aspects of the case is thus about as flawless as a legal argument can be. Any doubt must stem not from a deficiency in the argument based on the analogy to Title VI of the Civil Rights Act but from a disagreement as to whether a handicapped condition is fully analogous to race. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402 (D.D.C. 1983). Whether that doubt is justified or

not, however, courts are not the proper fora in which the reasonableness of the analogy to race is to be judged.

Selective refusals to be guided by precedents under Title VI of the Civil Rights Act are likely to lead to an incoherent body of interpretative law under Section 504. Ambiguity pervades the majority opinion as to exactly which services and which handicapped persons are excluded from the statute. All one can know for certain is that some medical services may be denied to some handicapped persons, without running afoul of Section 504. The majority even implies, *inter alia*, that Section 504 may not apply at all to the provision of medical services, since such services are inseparable from treatment decisions. This is in the face of the explicit statement of the Senate Report that it "was enacted to prevent discrimination against all handicapped individuals . . . in . . . health services," S. Rep. No. 1297, *supra*, *reprinted in* 1974 U.S. Code Cong. & Ad. News at 6388. If that interpretation stands, the handicapped will be deprived of a fairly won political victory and exposed to the possibility of future decisions excluding other services from coverage by Section 504. On the other hand, the majority opinion also implies that a narrower holding may be intended and that only certain kinds of handicapped persons are excluded. If that interpretation stands, then the federal courts may be forced to resolve individually each of these human tragedies and moral dilemmas. It was Judge Gesell's prediction in *American Academy of Pediatrics*, the precedent drawn upon so heavily by the majority, that Section 504 will require line-drawing in individual cases between the extremes of a failure to provide services to a mildly

handicapped child and a failure to use heroic measures to prolong for a period of time the life of an infant who has no hope of achieving even minimal consciousness. 561 F. Supp. at 402. Such a reading of Section 504, however, intrudes quite as profoundly upon medical decisions, parental judgments and state authority as the interpretation proffered by the government and thus undermines the reasoning of the majority.

Also, I would respectfully suggest that we act outside our legitimate area of authority in declining to follow the path staked out by Title VI of the Civil Rights Act. Congress did not adopt the analogy to race merely as a legislative means to a policy goal but was persuaded and politically energized by the view that the analogy was correct. A judicial failure to follow the analogy where it leads is an outright disagreement with Congress' judgment and an unconstitutional act in itself.

Finally, we facilitate the democratic legislative process by applying the analogy to race as adopted by the Congress. A political temptation to avoid confrontations with issues of moral or prudential controversy is an inevitable aspect of legislative deliberations. If courts are perceived as ready to "correct" overbroad legislation, Congress will find it ever more tempting to avoid its responsibility to address and resolve the highly delicate issues which may lurk in seemingly unobjectionable legislative proposals. Rhetorical flourishes will be substituted for statutory precision and "voids" in legislative histories will be ever more frequent. This is particularly so in cases involving legislative analogies to race. The moral and legal successes of the civil rights movement have prompted

many groups to seek legislation which puts a particular characteristic or condition on a legal par with race. So long as the courts are perceived to stand ready to consider tempering such legislation where it leads to controversial results, the path of least political resistance will always be for the Congress to avoid serious consideration of the actual consequences of legislating particular analogies to race. Only an apprehension that such legislative analogies will be enforced by courts as written can provide a counter incentive to induce Congress to address its legislative responsibilities.

II

I agree with that portion of the discussion in Part II A of Judge Pratt's opinion which concludes that we cannot determine on the present record whether the defendant hospital is a recipient of "financial federal assistance" within the meaning of Section 504 and whether the "program or activity" to which that section applies is the entire hospital. I would, therefore, reverse and remand so that the record can be amplified. In light of the pendency of *Grove City College v. Bell*, 687 F.2d 684 (3rd Cir. 1982), *cert. granted*, 103 S. Ct. 1181 (1983), argued Nov. 29, 1983, *see* 52 U.S.L.W. 3433 (U.S. Dec. 6, 1983) and in view of the majority's decision, further discussion of this issue by me would be superfluous.

For the reasons stated above, I dissent.

APPENDIX C

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638-CLB

AMERICAN HOSPITAL ASSOCIATION, ETC.,
HOSPITAL ASSOCIATION OF NEW YORK STATE, ETC.
and STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER, PLAINTIFFS

—against—

MARGARET M. HECKLER, Secretary,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES,
DEFENDANT

---

84 Civ. 1724-CLB

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS

—against—

MARGARET M. HECKLER, Secretary,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES,
DEFENDANT

MEMORANDUM AND ORDER

Brieant, J.

There being no material facts in dispute, the motions by plaintiffs for summary judgment are granted.

See transcripts of hearings on March 23, 1984 and April 9, 1984.

This consolidated case is directly controlled by the decision of our Court of Appeals in *United States* v. *University Hospital*, No. 83-6343 (2d Cir. February 23, 1984) (slip op.), *motion for rehearing en banc denied*, May 17, 1984.

The final regulations challenged by plaintiffs in this consolidated action, 45 C.F.R. § 84.55(b)-(e), 49 Fed. Reg. 1622, *et seq.* (January 12, 1984), were promulgated solely under the purported authority of § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 974, see 49 Fed. Reg. at 1622. Accordingly, in light of *University Hospital*, *supra*, they are invalid, unlawful and must be set aside pursuant to the Administrative Procedure Act, 5 U.S.C. § 706(2)(C), because promulgated without statutory authority.

In light of the denial of reconsideration *en banc* of *University Hospital*, *supra*, this Court finds it unnecessary to reach the constitutional issues raised by plaintiffs. Nor need the Court now consider the effect of the Supreme Court's decision in *Grove City College* v. *Bell*, —— U.S. ——, 52 U.S.L.W. 4283 (February 28, 1984), decided subsequent in time to the panel opinion in *University Hospital*, *supra*. See our Memorandum and Order dated May 11, 1984.

Settle final declaratory judgment on five (5) days notice.

So Ordered.

Dated: New York, New York
May 23, 1984

/s/ Charles L. Brieant
CHARLES L. BRIEANT
U.S.D.J.

APPENDIX D

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638-CLB

AMERICAN HOSPITAL ASSOCIATION, ET AL., PLAINTIFFS

—against—

MARGARET M. HECKLER, DEFENDANT

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84 Civ. 1724-CLB

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS

—against—

MARGARET M. HECKLER, DEFENDANT

FINAL JUDGMENT

Brieant, J.

WHEREAS, Plaintiffs have moved for summary judgment on Count I of their Complaint which seeks declaratory and permanent injunctive relief against Defendant's final regulations on "Procedures and Guidelines Relating to Health Care for Handicapped Infants," 45 C.F.R. §§ 84.55(b)-(e), 49 Fed. Reg. 1622 (January 12, 1984) [hereinafter the "Final Regulation"], and against any other actions by Defendant to investigate and regulate treatment involving impaired newborn infants taken under authority

of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, including currently pending investigation and other enforcement actions; and

WHEREAS, the Court has granted Plaintiffs' motion for summary judgment by Memorandum and Order dated May 23, 1984 because, under the decision in *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984), Defendant has no authority under Section 504 to investigate or to otherwise regulate treatment decisions involving impaired newborn infants;

NOW, it is hereby ORDERED that:

1. The Final Regulation and all actions implementing it are declared invalid and unlawful as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and thus have no further force or effect.

2. Any other actions of Defendant to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions, are declared invalid and unlawful as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and thus have no further force or effect.

3. Defendant, her officers, agents, employees and attorneys are permanently enjoined from any further implementation of the Final Regulation with respect to "any program or activity receiving Federal financial assistance." *See* 29 U.S.C. § 794 and 29 U.S.C. § 706(14).

4. Defendant, her officers, agents, employees and attorneys are also permanently enjoined from continuing or undertaking any other actions to investi-

gate or regulate treatment decisions involving impaired newborn infants taken under authority of Section 504, including pending investigation and other enforcement actions, with respect to "any program or activity receiving Federal financial assistance." *See* 29 U.S.C. § 794 and 29 U.S.C. § 706(14).

Dated: New York, New York
June 11, 1984

/s/ Charles L. Brieant
CHARLES L. BRIEANT
U.S. District Judge

APPENDIX E

45 C.F.R. 84.55 and 45 C.F.R. Pt. 84, App. C, as added by 49 Fed. Reg. 1650 *et seq.* (1984), provides:

PART 84—[AMENDED]

The authority citation for Part 84 is as follows:

Authority: Sec. 504, Rehabilitation Act of 1973, Pub. L. 93-112, 87 Stat. 394 (29 U.S.C. 794974) [*sic*]; sec. 111(a), Rehabilitation Act Amendments of 1974, Pub. L. 93-516, 88 Stat. 1619 (29 U.S.C. 706); sec. 606, Education of the Handicapped Act (20 U.S.C. 1405), as amended by Pub. L. 94-142, 89 Stat. 795; sec. 321, Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, 84 Stat. 182 (42 U.S.C. 4581), as amended; sec. 497, Drug Abuse Office and Treatment Act of 1972, 86 Stat. 78 (21 U.S.C. 1174), as amended.

For the reasons set forth in the preamble:

1. 45 CFR Part 84 is amended by inserting after § 84.54 the following new § 84.55:

§ 84.55 Procedures relating to health care for handicapped infants.

(a) *Infant Care Review Committees.* The Department encourages each recipient health care provider that provides health care services to infants in programs receiving Federal financial assistance to establish an Infant Care Review Committee (ICRC) to assist the provider in delivering health care and related services to infants and in complying with this part. The purpose of the committee is to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concern-

ing medically beneficial treatment in specific cases. While the Department recognizes the value of ICRC's in assuring appropriate medical care to infants, such committees are not required by this section. An ICRC should be composed of individuals representing a broad range of perspectives, and should include a practicing physician, a representative of a disability organization, a practicing nurse, and other individuals. A suggested model ICRC is set forth in paragraph (f) of this section.

(b) *Posting of informational notice.* (1) Each recipient health care provider that provides health care services to infants in programs or activities receiving Federal financial assistance shall post and keep posted in appropriate places an informational notice.

(2) The notice must be posted at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it, the notice need not be posted in area(s) where parents of infant patients will see it.

(3) Each health care provider for which the content of the following notice (identified as Notice A) is truthful may use Notice A. For the content of the notice to be truthful: (i) The provider must have a policy consistent with that stated in the notice; (ii) the provider must have a procedure for review of treatment deliberations and decisions to which the notice applies, such as (but not limited to) an Infant Care Review Committee; and (iii) the statements concerning the identity of callers and retaliation are truthful.

Notice A:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

(4) Health care providers other than those described in paragraph (b)(3) of this section must post the following notice (identified as Notice B):

Notice B:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and medi-

cally beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, applies to programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day: TDD capability.

The identity of callers will be held confidential. Federal regulations prohibit retaliation by this hospital against any person who provides information about possible violations.

(5) The notice may be no smaller than 5 by 7 inches, and the type size no smaller than that generally used for similar internal communications to staff. The recipient must insert the specified information on the notice it selects. Recipient hospitals in Washington, D.C. must list 863-0100 as the telephone number for HHS. No other alterations may be made to the notice. Copies of the notices may be obtained from the Department of Health and Human Services upon request, or the recipient may produce its own notices in conformance with the specified wording.

(c) *Responsibilities of recipient state child protective services agencies.* (1) Within 60 days of the effective date of this section, each recipient state child protective services agency shall establish and maintain in written form methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances

of unlawful medical neglect of handicapped infants. These methods of administration and procedures shall include:

(i) A requirement that health care providers report on a timely basis to the state agency circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants;

(ii) A method by which the state agency can receive reports of suspected unlawful medical neglect of handicapped infants from health care providers, other individuals, and the Department on a timely basis;

(iii) Immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports;

(iv) Provision of child protective services to such medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the provision of necessary nourishment and medical treatment; and

(v) Timely notification to the responsible Department official of each report of suspected unlawful medical neglect involving the withholding, solely on the basis of present or anticipated physical or mental impairments, of treatment or nourishment from a handicapped infant who, in spite of such impairments, will medically benefit from the treatment or nourishment, the steps taken by the state agency to investigate such report, and the state agency's final disposition of such report.

(2) Whenever a hospital at which an infant who is the subject of a report of suspected unlawful medical neglect is being treated has an Infant Care Re-

view Committee (ICRC) the Department encourages the state child protective services agency to consult with the ICRC in carrying out the state agency's authorities under its state law and methods of administration. In developing its methods of administration and procedures, the Department encourages child protective services agencies to adopt guidelines for investigations similar to those of the Department regarding the involvement of ICRC's.

(The provisions of § 84.55(c) have been approved by the Office of Management and Budget pursuant to the Paperwork Reduction Act. The OMB No. is 0990-0114.)

(d) *Expedited access to records.* Access to pertinent records and facilities of a recipient pursuant to 45 CFR 80.6(c) (made applicable to this part by 45 CFR 84.61) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

(e) *Expedited action to effect compliance.* The requirement of 45 CFR 80.8(d)(3) pertaining to notice to recipients prior to the initiation of action to effect compliance (made applicable to this part by 45 CFR 84.61) shall not apply when, in the judgment of the responsible Department official, immediate action to effect compliance is necessary to protect the life or health of a handicapped individual. In such cases the recipient will, as soon as practicable, be given oral or written notice of its failure to comply, of the action to be taken to effect compliance, and its continuing opportunity to comply voluntarily.

(f) *Model Infant Care Review Committee.* Recipient health care providers wishing to establish Infant Care Review Committees should consider adoption of

the following model. This model is advisory. Recipient health care providers are not required to establish a review committee or, if one is established, to adhere to this model. In seeking to determine compliance with this part, as it relates to health care for handicapped infants, by health care providers that have an ICRC established and operated substantially in accordance with this model, the Department will, to the extent possible, consult with the ICRC.

(1) *Establishment and purpose.* (i) The hospital establishes an Infant Care Review Committee (ICRC) or joins with one or more other hospitals to create a joint ICRC. The establishing document will state that the ICRC is for the purpose of facilitating the development and implementation of standards, policies and procedures designed to assure that, while respecting reasonable medical judgments, treatment and nourishment not be withheld, solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite of such impairments, will benefit medically from the treatment or nourishment.

(ii) The activities of the ICRC will be guided by the following principles:

(A) The interpretative guidelines of the Department relating to the applicability of this part to health care for handicapped infants.

(B) As stated in the "Principles of Treatment of Disabled Infants" of the coalition of major medical and disability organizations, including the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association, and others:

When medical care is clearly beneficial, it should always be provided. When appropriate medical care

is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

(C) As stated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

This (standard for providing medically beneficial treatment) is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to

undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

(iii) The ICRC will carry out its purposes by:

(A) Recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for ICRC action for specific categories of life-threatening conditions affecting infants;

(B) Providing advice in specific cases when decisions are being considered to withhold or withdraw from infant life-sustaining medical or surgical treatment; and

(C) Reviewing retrospectively on a regular basis infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.

(2) *Organization and staffing.* The ICRC will consist of at least 7 members and include the following:

(i) A practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon),

(ii) A practicing nurse,

(iii) A hospital administrator,

(iv) A representative of the legal profession,

(v) A representative of a disability group, or a developmental disability expert,

(vi) A lay community member, and

(vii) A member of a facility's organized medical staff, who shall serve as chairperson.

In connection with review of specific cases, one member of the ICRC shall be designated to act as "special advocate" for the infant, as provided in par-

agraph (f)(3)(ii)(E) of the section. The hospital will provide staff support for the ICRC, including legal counsel. The ICRC will meet on a regular basis, or as required below in connection with review of specific cases. It shall adopt or recommend to the appropriate hospital official or body such administrative policies as terms of office and quorum requirements. The ICRC will recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability on a 24-hour basis.

(3) *Operation of ICRC*—(i) *Prospective policy development.* (A) The ICRC will develop and recommend for adoption by the hospital institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These will include guidelines for management of specific types of cases or diagnoses, for example, Down's syndrome and spina bifida, and procedures to be followed in such recurring circumstances as, for example, brain death and parental refusal to consent to life-saving treatment. The hospital, upon recommendation of the ICRC, may require attending physicians to notify the ICRC of the presence in the facility of an infant with a diagnosis specified by the ICRC, e.g., Down's syndrome and spina bifida.

(B) In recommending these policies and guidelines, the ICRC will consult with medical and other authorities on issues involving disabled individuals, e.g., neonatologists, pediatric surgeons, county and city agencies which provide services for the disabled, and disability advocacy organizations. It will also consult with appropriate committees of the medical staff, to ensure that the ICRC policies and guidelines build on

existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The ICRC will also inform and educate hospital staff on the policies and guidelines it develops.

(ii) *Review of specific cases.* In addition to regularly scheduled meetings, interim ICRC meetings will take place under specified circumstances to permit review of individual cases. The hospital will, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice.

(A) Interim ICRC meetings will be convened within 24 hours (or less if indicated) when there is disagreement between the family of an infant and the infant's physician as to the withholding or withdrawal of treatment, when a preliminary decision to withhold or withdraw life-sustaining treatment has been made in certain categories of cases identified by the ICRC, when there is disagreement between members of the hospital's medical and/or nursing staffs, or when otherwise appropriate.

(B) Such interim ICRC meetings will take place upon the request of any member of the ICRC or hospital staff or parent or guardian of the infant. The ICRC will have procedures to preserve the confidentiality of the identity of persons making such requests, and such persons shall be protected from reprisal. When appropriate, the ICRC or a designated member will inform the requesting individual of the ICRC's recommendation.

(C) The ICRC may provide for telephone and other forms of review when the timing and nature of the case, as identified in policies developed by the ICRC, make the convening of an interim meeting impracticable.

(D) Interim meetings will be open to the affected parties. The ICRC will ensure that the interests of the parents, the physician, and the child are fully considered; that family members have been fully informed of the patient's condition and prognosis; that they have been provided with a listing which describes the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the ICRC; and that the ICRC will facilitate their access to such services and groups.

(E) To ensure a comprehensive evaluation of all options and factors pertinent to the committee's deliberations, the chairperson will designate one member of the ICRC to act, in connection with that specific case, as special advocate for the infant. The special advocate will seek to ensure that all considerations in favor of the provision of life-sustaining treatment are fully evaluated and considered by the ICRC.

(F) In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the family's wishes will be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the ICRC, after due deliberation, agrees with the family, the ICRC will recommend that the treatment be withheld. When there is physician/family disagreement and the family refuses consent, but the ICRC disagrees with the family, the ICRC will recommend to the hospital board or appropriate official that the case be referred immediately to an appropriate court or child protective agency, and every effort shall be

made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action. The ICRC will also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdrawn, but the ICRC disagrees.

(iii) *Retrospective record review.* The ICRC, at its regularly-scheduled meeting, will review all records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed by the ICRC, unless the case was previously before the ICRC pursuant to paragraph (f)(3)(ii) of this section. If the ICRC finds that a deviation was made from the institutional policies in a given case, it shall conduct a review and report the findings to appropriate hospital personnel for appropriate action.

(4) *Records.* The ICRC will maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records will be kept in accordance with institutional policies on confidentiality of medical information. They will be made available to appropriate government agencies, or upon court order, or as otherwise required by law.

Amendment to Table of Contents

2. The table of contents to 45 CFR Part 84 is amended by striking the designation of "84.55-84.60 [Reserved]" and by inserting in lieu thereof, the following:

Sec.

84.55 Procedures relating to health care for handicapped infants.

84.56-84.60 [Reserved]

3. 45 CFR Part 84 is amended by inserting after Appendix B the following new appendix:

Appendix C—Guidelines Relating to Health Care for Handicapped Infants.

(a) *Interpretative guidelines relating to the applicability of this part to health care for handicapped infants.* The following are interpretative guidelines of the Department set forth here to assist recipients and the public in understanding the Department's interpretation of section 504 and the regulations contained in this part as applied to matters concerning health care for handicapped infants. These interpretative guidelines are illustrative; they do not independently establish rules of conduct.

(1) With respect to programs and activities receiving Federal financial assistance, health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

(2) Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant.

(3) In determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.

(4) Section 504 and the provisions of this part are not applicable to parents (who are not recipients of Federal financial assistance). However, each recipient health care provider must in all aspects of its health care programs receiving Federal financial assistance provide health care and related services in a manner consistent with the requirements of section 504 and this part. Such aspects includes decisions on whether to report, as required by State law or otherwise, to the appropriate child protective services agency a suspected instance of medical neglect of a child, or to take other action to seek review or [*sic*] parental decisions to withhold consent for medically indicated treatment. Whenever parents make a decision to withhold consent for medically beneficial treatment or nourishment, such recipient providers may not, solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such incidents to the child protective services agency or to seek judicial review.

(5) The following are examples of applying these interpretative guidelines. These examples are stated in the context of decisions made by recipient health care providers. Were these decisions made by parents, the guideline stated in section (a)(4) would apply. These examples assume no facts or complications other than those stated. Because every case must be examined on its individual facts, these are merely illustrative examples to assist in understanding the framework for applying the nondiscrimination requirements of section 504 and this part.

(i) Withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome when the withholding is based

upon the anticipated future mental retardation of the infant and there are no medical contraindications to the surgery that would otherwise justify withholding the surgery would constitute a discriminatory act, violative of section 504.

(ii) Withholding of treatment for medically correctable physical anomalies in children born with spina bifida when such denial is based on anticipated mental impairment, paralysis or incontinence of the infant, rather than on reasonable medical judgments that treatment would be futile, too unlikely of success given complications in the particular case, or otherwise not of medical benefit to the infant, would constitute a discriminatory act, violative of section 504.

(iii) Withholding of medical treatment for an infant born with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.

(iv) Withholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504.

(b) *Guidelines for HHS investigations relating to health care for handicapped infants.* The following are guidelines of the Department in conducting investigations relating to health care for handicapped infants. They are set forth here to assist recipients and the public in understanding applicable investigative procedures. These guidelines do not establish rules of conduct, create or affect legally enforceable

rights of any person, or modify existing rights, authorities or responsibilities pursuant to this part. These guidelines reflect the Department's recognition of the special circumstances presented in connection with complaints of suspected life-threatening noncompliance with this part involving health care for handicapped infants. These guidelines do not apply to other investigations pursuant to this part, or other civil rights statutes and rules. Deviations from these guidelines may occur when, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant.

(1) Unless impracticable, whenever the Department receives a complaint of suspected life-threatening noncompliance with this part in connection with health care for a handicapped infant in a program or activity receiving Federal financial assistance, HHS will immediately conduct a preliminary inquiry into the matter by initiating telephone contact with the recipient hospital to obtain information relating to the condition and treatment of the infant who is the subject of the complaint. The preliminary inquiry, which may include additional contact with the complainant and a requirement that pertinent records be provided to the Department, will generally be completed within 24 hours (or sooner if indicated) after receipt of the complaint.

(2) Unless impracticable, whenever a recipient hospital has an Infant Care Review Committee, established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the Department will, as part of its preliminary inquiry, solicit the information available to, and the analysis and recommendations of, the ICRC. Unless, in the judg-

ment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant, prior to initiating an on-site investigation, the Department will await receipt of this information from the ICRC for 24 hours (or less if indicated) after receipt of the complaint. The Department may require a subsequent written report of the ICRC's findings, accompanied by pertinent records and documentation.

(3) On the basis of the information obtained during preliminary inquiry, including information provided by the hospital (including the hospital's ICRC, if any), information provided by the complainant, and all other information obtained, the Department will determine whether there is a need for an on-site investigation of the complaint. Whenever the Department determines that doubt remains that the recipient hospital or some other recipient is in compliance with this part or additional documentation is desired to substantiate a conclusion, the Department will initiate an on-site investigation or take some other appropriate action. Unless impracticable, prior to initiating an on-site investigation, the Department's medical consultant (referred to in paragraph 6) will contact the hospital's ICRC or appropriate medical personnel of the recipient hospital.

(4) In conducting on-site investigations, when a recipient hospital has an ICRC established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the investigation will begin with, or include at the earliest practicable time, a meeting with the ICRC or its designees. In all on-site investigations, the Department will make every effort to minimize any potential inconvenience or disruption, accommodate the schedules of health care profes-

sionals and avoid making medical records unavailable. The Department will also seek to coordinate its investigation with any related investigations by the state child protective services agency so as to minimize potential disruption.

(5) It is the policy of the Department to make no comment to the public or media regarding the substance of a pending preliminary inquiry or investigation.

(6) The Department will obtain the assistance of a qualified medical consultant to evaluate the medical information (including medical records) obtained in the course of a preliminary inquiry or investigation. The name, title and telephone number of the Department's medical consultant will be made available to the recipient hospital. The Department's medical consultant will, if appropriate, contact medical personnel of the recipient hospital in connection with the preliminary inquiry, investigation or medical consultant's evaluation. To the extent practicable, the medical consultant will be a specialist with respect to the condition of the infant who is the subject of the preliminary inquiry or investigation. The medical consultant may be an employee of the Department or another person who has agreed to serve, with or without compensation, in that capacity.

(7) The Department will advise the recipient hospital of its conclusions as soon as possible following the completion of a preliminary inquiry or investigation. Whenever final administrative findings following an investigation of a complaint of suspected life-threatening noncompliance cannot be made promptly, the Department will seek to notify the recipient and the complainant of the Department's decision on whether the matter will be immediately referred to the Department of Justice pursuant to 45 CFR 80.8.

(8) Except as necessary to determine or effect compliance, the Department will (i) in conducting preliminary inquiries and investigations, permit information provided by the recipient hospital to the Department to be furnished without names or other identifying information relating to the infant and the infant's family; and (ii) to the extent permitted by law, safeguard the confidentiality of information obtained.

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Petition for a Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF THE RESPONDENTS AMERICAN MEDICAL ASSOCIATION, ET AL., IN OPPOSITION

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QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, authorizes:

(a) a direct federal role investigating and regulating individual treatment decisions involving severely impaired newborn infants, which intrudes on the states' traditional responsibilities for regulating parent-child and physician-patient relationships; and

(b) the inevitable creation of a body of "504 malpractice law" for determining whether individual treatment decisions in the complex and rapidly evolving area of medical care for severely impaired newborns are "reasonable" or "unreasonable" under federal standards.

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

No. 84-1529

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Petition for a Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF THE RESPONDENTS AMERICAN MEDICAL ASSOCIATION, ET AL., IN OPPOSITION

The American Medical Association ("AMA"), the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Academy of Family Physicians, the Hospital Association of New York State, the American Hospital Association and certain individual physicians ("respondents AMA *et al.*") oppose the petition for a writ of certiorari filed by Margaret M. Heckler ("the Secretary"), the Secretary of Health and Human Services ("HHS").

The Secretary seeks review of a decision by the United States Court of Appeals for the Second Circuit invalidating a regulation issued by the Secretary pursuant to Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 ("the 504 Regulation") (Pet. App. 53a-58a), which authorizes direct federal investigation and regulation of individual treatment decisions made by parents on behalf of their severely impaired children in consultation with

the physician of their choice. The regulation also places "*independent federal dut*[*ies*]" on hospitals and other providers of health services with regard "to the treatment" of severely impaired infants. Pet. 27 n.22 (emphasis supplied).

Review by this Court is not warranted. First, Section 504 clearly does not authorize direct federal investigation of individual treatment decisions involving impaired newborns—a federal role that would unnecessarily duplicate and inevitably subvert the states' traditional responsibilities for regulating individual parent-child and doctor-patient relationships. Second, the federal interest with respect to treatment of impaired newborns is reflected not in the 504 Regulation promulgated solely by the Secretary but in the 1984 Child Abuse Amendments, Pub. L. No. 98-457, 98 Stat. 1749 (1984), enacted by the Congress last fall after the 504 Regulation had been invalidated. This new legislation uses a state grant program and state agencies to address federal concerns and expressly repudiates a direct federal regulatory role and creation of a federal bureaucracy to enforce the federal "504 malpractice" standards which are inherent in the Secretary's voided approach.

STATEMENT

The Secretary's statement of the case (Pet. 2-11) is profoundly misleading because it fails to describe adequately or ignores completely the following crucial dimensions of the problem of proper care for impaired newborns: the historic state law framework which regulates parent-child and physician-patient relationships; the complex medical and ethical issues raised by treatment decisions for impaired newborns; the growth of voluntarily-created, hospital-based infant care review committees which provide a non-governmental response to the difficult issues that arise in this area; the facts of *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984) (Pet. App. 4a-47a), which demonstrate fully how overbearing, intrusive and unnecessary is the federal gov-

ernment's attempt under Section 504 to regulate individual treatment decisions directly; and the Congress' explicit decision in the 1984 Child Abuse Amendments to reject, on policy grounds, the direct federal investigatory and regulatory role advanced by the Secretary here.

(1) *The State Law Framework.* The public dialogue about appropriate medical treatment of severely impaired newborn infants takes place within an historic state law framework which cedes to parents the ultimate responsibility for making decisions about treatment of their seriously ill children. 50 Fed. Reg. 14880 (April 15, 1985).[1] Parental treatment decisions on behalf of their children are controlling, except in the most extreme cases when state courts have determined that a decision not to authorize treatment constitutes "medical neglect" of children by their parents. *Id.*

All fifty states have child protective service agencies which are generally responsible for investigating reports of child abuse and neglect by parents (including "medical neglect"), counseling families and, where necessary, instituting court actions to remove the parent as decision maker for the child. *Id.* at 14878. Moreover, most hospitals have established procedures for working with the state child protective service agencies and seeking state court orders directing that appropriate medical treatment be given to an infant when the parents are clearly not acting in the best interest of the child. *See* 49 Fed. Reg. 1631 (1984).

State law also has historically governed the relationship between patients and physicians.[2] Unless parents

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[1] This Court already has recognized the primacy of the parents' role in making difficult treatment decisions for their children. *See Parham* v. *J.R.*, 442 U.S. 584, 602 (1979) (historically law has recognized that natural bonds of affection lead parents to act in the best interests of their children).

[2] *See Barsky* v. *Board of Regents*, 347 U.S. 442 (1954); *Linder* v. *United States*, 268 U.S. 5 (1925); *Dent* v. *West Virginia*, 129 U.S. 114 (1889).

consent to treatment, a physician commits battery if he or she operates on a minor. *See* note 16, *infra*. All states have mandatory reporting statutes which require physicians (and other health care professionals) to inform the state child protective service agency of known or suspected instances of medical neglect by parents.[3] Moreover, once a physician has been engaged by a patient (or by a parent on behalf of a minor patient) and consent to treatment has been given, then under state statutory or common law the physician has a legal duty to provide appropriate medical care until the doctor-patient relationship is terminated by giving the patient due notice and the opportunity to obtain other medical care. If the physician withdraws before these conditions are satisfied, then he or she is liable for damages under the doctrine of patient abandonment.[4]

The Secretary attempts to mislead this Court by vaguely citing to the "Baby Doe of Indiana" case ("Bloomington Baby Doe") to illustrate the "problem" with the historic state law framework which, in her view, justifies a direct federal role. Pet. 2-3, 20. But, as discussed *infra*, pp. 27-28, both private health care providers

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[3] *See generally* S. Cohen & A. Sussman, Reporting Child Abuse and Neglect (1975); Besharov, *The Legal Aspects of Reporting Known and Suspected Child Abuse and Neglect*, 23 Vill. L. Rev. 458 (1977-1978).

[4] *See* 1 D. Louisell & H. Williams, Medical Malpractice ¶¶ 4.12, 8.08 (Rev. ed. 1984); A. Holder, Medical Malpractice Law 374-393 (1975). Widely accepted principles of medical ethics impose a similar duty on physicians to continue necessary treatment until the physician-patient relationship has been properly terminated in a manner which allows engagement of another physician. AMA, Current Opinions of the Judicial Council § 8.10 (1984).

In addition, medical licensing statutes in many states provide for the revocation or suspension of a physician's license, or other disciplinary action, upon a finding, *inter alia*, that the physician has abandoned his or her patient by refusing to provide needed treatment. *See, e.g.*, Cal. Bus. & Prof. Code § 2234 (West 1985 Supp.); Ill. Ann. Stat. ch. 111, § 4433 (Smith-Hurd 1984-85 Supp.); N.Y. Educ. Law § 6509 (McKinney's 1984 Supp.).

and state executive branch officials sought judicial review of the parental treatment decision in that case. Two different state court judges refused to overturn the parents' treatment choice, and those state *judicial* decisions are clearly not subject to federal regulation under Section 504. The actions of health care providers and state officials in taking a rare case of questionable parental decisionmaking to state court shows that state laws and institutions are working.

(2) *Medical and Ethical Context: The Growth of Infant Care Review Committees.* The question of what sort of medical treatment, if any, should be given to severely impaired newborn infants is "one of the most difficult and sensitive medical and ethical problems facing our society." *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 396 (D.D.C. 1983) (Gesell, J.). The birth of such an infant is often an unexpected and traumatic event for parents, who are confronted with the necessity of making difficult life or death treatment decisions with little advance warning. *See* R. Stinson & P. Stinson, The Long Dying of Baby Andrew (1983). The difficulties for parents become acute when a particular condition is so serious that severe disability will remain even after treatment of that condition or when an infant has multiple impairments, one that is correctable and one, like anencephaly (entire or substantial absence of a brain), which will have an enormous, adverse impact on the child.[5]

In some cases involving impaired newborn infants, physicians can predict with a relative degree of confidence that a particular course of treatment is likely to be beneficial or futile.[6] But there is a significant area of

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[5] *See generally* A. Rudolph, Pediatrics (17th ed. 1983); W. Nelson, Textbook of Pediatrics (R. McKay & V. Vaughan ed. 1975).

[6] *See* Affidavit of Peter A.M. Auld, M.D., professor of Pediatrics and Obstetrics and Perinatal Medicine at Cornell University Medical College, ¶ 2. Plaintiffs-respondents AMA *et al.* submitted affi-

uncertainty in which the results and consequences of a given course of treatment are simply unpredictable and the selection of an appropriate course of treatment becomes commensurately more difficult. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research stated in its recent report, Deciding to Forego Life-Sustaining Treatment 220 (1983) [*"President's Commission Report"*]:

> Much of the difficulty in these [ambiguous] cases arises from factual uncertainty. For the many infants born prematurely, and sometimes for those with serious congenital defects, the only certainty is that without intensive care they are unlikely to survive; very little is known about how each individual will fare with treatment. Neonatology is too new a field to allow accurate predictions of which babies will survive and of the complications, handicaps, and potentials that the survivors might have. (Footnote omitted.)

Recent advances in neonatal medicine have also exacerbated the uncertainty in treatment decisions. As the President's Commission Report explained (at p. 198):

> [M]edicine's increased ability to forestall death in seriously ill newborns has magnified the already difficult task of physicians and parents who must attempt to assess which infants will benefit from various medical interventions, and which will not. Not only does this test the limits of medical certainty in diagnosis and prognosis, it also raises profound ethical issues.

To address the difficult ethical issues which can be raised by the birth of a severely impaired child, the President's Commission Report (at p. 225-228) repudi-

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davits and other evidentiary material in support of their motion for summary judgment in this case. In her defense, the Secretary did not submit *any* testimonial evidence on medical issues. Citations to affidavits in this opposition thus refer to the uncontested testimony submitted to the District Court by the AMA *et al.*

ated an increased federal role like the one advanced by the Secretary in the 504 Regulation and, instead, recommended the voluntary formation of infant care review committees. Medical associations have also advocated the formation of such committees.[7] These committees deal directly with the fundamental problem in this sensitive area: lack of information and perspective by the parents who must make decisions for their severely impaired infant. *President's Commission Report* at 227. Such committees are comprised of health professionals and, often, of individuals trained in other specialties such as religion, social work, ethics and law. The committees offer parents information, counseling and, where appropriate, review of proposed treatment decisions made in consultation with the attending physician. At present, many hospitals with intensive care units for neonates have some form of special review process for these difficult cases, and the number of infant care review committees is growing rapidly. 50 Fed. Reg. 14887 (April 15, 1985).

(3) *The Voided 504 Regulation.* Instead of following the recommendation of the President's Commission Report, the Secretary adopted the approach invalidated below which injects the federal government directly into individual treatment decisions. The 504 Regulation contains four mandatory provisions which were declared unlawful and enjoined in this case.[8] (i) The regulation re-

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[7] *See President's Commission Report* at 227-228; AMA, Judicial Council Report, *Guidelines for Ethics Committees in Health Care Institutions*, 253 J.A.M.A. 2698 (1985); American Academy of Pediatrics, *Guidelines for Infant Bioethics Committees* (1984).

[8] *See* 45 C.F.R. §§ 84.55(b)-(e). (Pet. App. 54a-58a.) The 504 Regulation also contains several non-mandatory provisions which were not challenged in this case. First, the regulation encourages, but does not require, health care providers to establish infant care review committees and sets forth a model rule for the establishment of such committees. 45 C.F.R. §§ 84.55(a), (f). (Pet. App. 53a-54a, 58a-62a.) Second, an Appendix to the regulation contains "interpretative guidelines" illustrating how the rule might apply to

quires recipient hospitals to post a notice, where health care professionals will see it, which states, in part, that discriminatory failure to provide "medically beneficial" treatment to an impaired newborn violates Section 504. The phrase "medically beneficial treatment" is not defined in the required notice. The notice must include the telephone number of a 24-hour a day hotline where any person may call federal officials to report suspected violations, even if such reports are based on nothing more than rumor. 45 C.F.R. § 84.55(b). (Pet. App. 54a.)

(ii) The 504 Regulation provides that recipient state child protective service agencies must establish and maintain in written form "methods of administration and procedures to assure that the agency utilizes its full authority *pursuant to state law* to prevent instances of unlawful *medical neglect* of handicapped infants." 45 C.F.R. § 84.55(c) (emphasis supplied). (Pet. App. 56a.) These "methods and procedures" include a *federal* requirement that physicians and other health care providers must report on a timely basis to the state agency "circumstances which they determine to constitute *known* or *suspected instances of unlawful medical neglect* of handicapped infants." *Id.* (emphasis supplied).

(iii) The 504 Regulation grants HHS expedited access to pertinent medical records and facilities and authorizes expedited investigations whenever HHS determines that immediate action is necessary to protect the life or health of an infant. 45 C.F.R. § 84.55(d). (Pet. App. 58a.)

(iv) The 504 Regulation also authorizes expedited action by HHS against federal fund recipients to effect compliance with Section 504, including court action. 45 C.F.R. § 84.55(e). (Pet. App. 58a.)

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particular treatment situations. 45 C.F.R. § 84.55, Appendix C, ¶ (a). (Pet. App. 66a-68a.) Finally, the Appendix sets forth "interpretative guidelines" for the conduct of HHS investigations. 45 C.F.R. § 84.55, Appendix C, ¶ (b). (Pet. App. 68a-72a.)

(4) *The Decisions Below.* The actions of the Secretary in *University Hospital*—which are conspicuously absent from her description of that case (Pet. 8-9)—perfectly illustrate the intrusive and unnecessary role of the federal government in second-guessing parents and state authorities under Section 504. After Baby Jane Doe was born with multiple birth defects on October 11, 1983, her parents decided not to authorize certain surgery following consultation with "several physicians, nurses, religious advisors, a social worker, and members of their family." (Pet. App. 6a.) A third party, unrelated to Baby Jane Doe, filed suit in New York State court seeking appointment of a guardian *ad litem* and an order directing that the surgery be performed. The trial court granted this request, but was immediately overruled by the Appellate Division, which determined that the parents' decision was in the best interests of the child. (Pet. App. 7a.) The New York Court of Appeals affirmed. (Pet. App. 7a-8a.)

While the state court proceedings were still in progress, the federal government, which had received a 504 complaint from an unidentified citizen, referred the matter to the New York State child protective service agency. That agency concluded on November 7, 1983 that there was no cause for state intervention against the parents. (Pet. App. 8a.) Without waiting for the state agency to make its determination, HHS in late October began its own direct Section 504 investigation. University Hospital declined to give Baby Jane Doe's medical records to HHS, based in part on the parents' refusal to release them. On November 2, 1983, *before* the state child protective service agency had reached a decision, HHS brought an action under Section 504 in federal court seeking access to the records. The Department then persisted in its suit even after the state agency concluded that no state intervention was warranted under New York's child neglect statute. (Pet. App. 8a-10a.) To protect their interests, Baby Jane Doe's parents were forced to intervene.

Baby Jane Doe's parents were thus required to defend not only a state court action and a state child protective service agency inquiry but a separate and independent federal lawsuit instituted by the United States. This harassing federal action exposed the parents to continued, unwanted publicity and imposed on them over $75,000 in additional legal fees. *See* 130 Cong. Rec. S8017 (daily ed. June 21, 1984). The District Court entered summary judgment for University Hospital and the parents. (Pet. App. 11a.) On February 23, 1984, the Court of Appeals affirmed, rejecting the Department's claim of authority to investigate Baby Jane Doe's parents and University Hospital. The Court of Appeals held that Section 504 does not "apply to treatment decisions involving defective newborn infants." (Pet. App. 40a.) The Secretary did not petition this Court for review of the Court of Appeals' decision in *University Hospital.*

The final 504 Regulation at issue in this proceeding was promulgated by the Secretary on January 12, 1984, while the *University Hospital* case was pending before the Court of Appeals.[9] After publication of this final 504 Regulation and after the Court of Appeals decision in *University Hospital,* the AMA *et al.* filed this action on March 12, 1984, in the District Court for the Southern District of New York.[10] On May 23, 1984, the District Court issued a memorandum and order which held that,

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[9] The Secretary's investigation and initiation of court action in *University Hospital* were undertaken in the fall of 1983 pursuant to her general authority under Section 504 but in the absence of a specific implementing regulation. The final 504 Regulation was not adopted until January 12, 1984, after the *University Hospital* case had been briefed, argued and submitted to the Court of Appeals for decision.

[10] On the same day, the American Hospital Association, the Hospital Association of New York State and Strong Memorial Hospital, which had previously filed an action in the same court challenging the validity of the Secretary's March 7, 1983 interim rule (48 Fed. Reg. 9630 (1983)) amended their complaint to state a claim challenging the lawfulness of the final 504 Regulation.

under authority of *University Hospital*, the 504 Regulation was invalid because the Secretary "has no authority under Section 504 to investigate or to otherwise regulate treatment decisions involving impaired newborn infants." (Pet. App. 51a.) The Court of Appeals, also relying on the controlling effect of *University Hospital*, affirmed in a two paragraph order. (Pet. App. 2a.)

(5) *The Child Abuse Amendments of 1984.* After holding that neither the express language nor the legislative history of Section 504 authorized the direct federal intrusion into historic state functions contemplated by the Secretary, the Court of Appeals concluded its opinion in *University Hospital* by noting (Pet. App. 40a-41a) that:

> it is congress, rather than an executive agency, that must weigh the competing interests at stake in this context in the first instance. Until congress has spoken, it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.

Following the invalidation of the 504 Regulation in this case, the Congress last year undertook just such an examination. It chose not to revive the direct federal investigatory and regulatory role advanced by the Secretary and voided by the courts.

Instead, the Congress in the fall of 1984 enacted the Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984), amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101 *et seq.* In contrast to Section 504, the Child Abuse Prevention and Treatment Act is a state grant program which seeks to help state child protective service agencies discharge *their* responsibilities with respect to abused and neglected children in the context of severely impaired newborn infants.[11] As a principal sponsor of the 1984 Child Abuse

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[11] The 1984 Child Abuse Amendments contemplate grants to state child protective service agencies conditioned on incorporation of

Amendments stated in a crucial piece of the legislative history:

> Throughout the statutory language and accompanying explanatory material, we refer to *authority under state law* as the mechanism for pursuing legal remedies under our amendment. *This legislation does not itself authorize direct federal involvement in individual cases.*[12] (Emphasis supplied.)

The Congress recognized that in enacting the 1984 Amendments, it was, for the first time, expressly addressing the difficult issues arising out of treatment of impaired newborns. In floor debates on the Conference Report, Representative Bartlett stated that "these Baby Doe provisions are *precedent setting.* They represent the first time that we have successfully legislated in a very sensitive area." 130 Cong. Rec. H10329 (daily ed. September 26, 1984) (emphasis supplied).[13] Moreover, in

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certain changes in state law and procedure consistent with the provisions of the Amendments. A definition of child neglect in the circumstance of withholding treatment from a severely disabled child is set forth; states must adopt certain reporting and other procedures; and the direct federal role is limited to training and a clearinghouse function for information relating to developments in treatment and support services for impaired newborns. *See* H.R. Conf. Rep. No. 1038, 98th Cong., 2nd Sess. (1984). *See also* 130 Cong. Rec. H10327 (daily ed. September 26, 1984); 130 Cong. Rec. S12382 (daily ed. September 28, 1984) (conference report debates on floor of House and Senate).

[12] Letter from Senator Hatch to Senator Weicker, 130 Cong. Rec. S12392 (daily ed. September 28, 1984). *See also* Pet. 27 (no direct federal role in individual cases is authorized).

[13] Representative Erlenborn noted that the "disabled infants provisions incorporated in the conference report address a myriad of difficult social and ethical issues. The conference agreement is the product of months of painstaking deliberations." *Id.* at H10333. Senators also explained how the Amendments embodied a new approach and an attempt to craft specific provisions to meet difficult problems. *See, e.g.,* 130 Cong. Rec. S12382-83, S12385, S12389 (daily ed. Sept. 28, 1984) (remarks of Senators Hatch, Dodd and Cranston).

the preamble to the final regulation implementing the 1984 Child Abuse Amendments ("1984 Child Abuse Regulation"), the Secretary noted the special and explicit Congressional effort to deal with the complex problems in this sensitive area (50 Fed. Reg. 14879 (April 15, 1985)):

> [T]his legislation [the 1984 Child Abuse Amendments] was the product of an extraordinary effort on the part of several Senators and Congressmen and representatives of a wide range of medical, right-to-life and disability organizations to forge a substantial consensus on an effective and workable program to assure the provision of appropriate medical care to disabled infants. . . .
>
> *It is clear that the legislation represented a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities.* (Emphasis supplied.)

REASONS FOR DENYING THE PETITION

In contrast to the 1984 Child Abuse Amendments enacted by the Congress, the 504 Regulation promulgated solely by the Secretary reflects neither clear congressional authorization nor a careful balancing of the relevant interests. Accordingly, this case does not warrant plenary review by this Court.

First, the Secretary's attempt to investigate and regulate individual treatment decisions involving impaired newborns is clearly not authorized by the language of Section 504. Parents are not recipients of "federal financial assistance" and their treatment decisions on behalf of their infants may not be regulated under Section 504. Similarly, the independent state law duties regarding parental neglect imposed on health care providers are not part of any federally funded "program or activity," and providers' decisions whether to report or prosecute par-

ents for medical neglect are similarly outside the scope of Section 504. Moreover, the Congress clearly did not intend to subvert the historic state law framework for regulating parent-child and doctor-patient relationships and create a body of "504 malpractice law" for determining, according to federal standards, the reasonableness of individual treatment decisions.

Second, there is no substantial federal interest in the voided regulations because, *inter alia*, the Secretary has shown no problem with the historic state law framework that justifies a direct federal role, and the Congress has explicitly and recently adopted an alternative state-based approach in the 1984 Child Abuse Amendments.

I. THE DECISION BELOW WAS CLEARLY CORRECT: SECTION 504 DOES NOT AUTHORIZE DIRECT FEDERAL INVESTIGATION AND REGULATION OF INDIVIDUAL TREATMENT DECISIONS INVOLVING IMPAIRED NEWBORNS.

With respect to "treatment" of impaired newborns, there are three types of decisions which the Secretary's petition seems to suggest are within the scope of Section 504: [14] the decision by parents whether or not to consent to treatment for their child (Pet. 6); the decision by a health care provider whether or not to report to state agencies, or seek state court action against, a parent on grounds of medical neglect (*id.*); and the decision by a physician or hospital whether or not to treat an infant if the parents have consented to treatment (*id.* at 11-12, 19-20). But, despite the Secretary's studied vagueness as to what conduct by whom actually violates Section 504, the Congress clearly intended that none of these types of decisions should be directly regulated by HHS under authority of that provision.

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[14] Section 504 provides, in pertinent part: "No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial Assistance . . . ." 29 U.S.C. § 794.

A. Treatment Decisions by Parents on Behalf of Their Impaired Newborn Infants Are Not Within the Scope of Section 504.

Although the Secretary withholds this fact from the Court, she has conceded elsewhere that, absent state court action, parents are the sole decisionmakers for their infant children and that parental treatment decisions on behalf of impaired newborns are not within the scope of Section 504 because parents are not recipients of "federal financial assistance."

As noted, parents have the ultimate responsibility for making decisions about the treatment of seriously ill newborns.[15] As the Secretary recently stated in the preamble to the Child Abuse Regulation,

> The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian. *Parents are the decision makers concerning treatment for their disabled infant, based on the advice and reasonable medical judgment of their physician (or physicians)*. (Emphasis supplied.)

50 Fed. Reg. 14880 (April 15, 1985). Indeed, physicians, nurses and hospitals have no authority to perform treatment on newborn infants to which parents have not consented on behalf of their child.[16]

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[15] State law has always recognized the parents' inherent right to make medical decisions on behalf of their minor children. *See, e.g., Bennett* v. *Jeffreys*, 40 N.Y.2d 543, 356 N.E.2d 277 (1976); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (Wash. 1942). Parental autonomy to make decisions for their children is also protected under the Constitution. *See, e.g., Wisconsin* v. *Yoder*, 406 U.S. 205 (1972); *Meyer* v. *Nebraska*, 262 U.S. 390 (1923); *Pierce* v. *Society of Sisters*, 268 U.S. 510 (1925).

[16] A physician or hospital is guilty of assault and battery if surgery is performed on an infant without parental consent. *See* Prosser and Keeton on the Law of Torts § 18, at 116 (W. Keeton ed. 1984). *See also Schloendorff* v. *Society of New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (1914).

After conceding that, absent a court order, only parents can make treatment decisions for their infant children, the Secretary then makes the further, devastating concession that parental decisionmaking is outside the scope of Section 504 because parents are not recipients of "federal financial assistance." In the preamble to the 504 Regulation voided below, the Secretary stated:

> Section 504 applies only to programs or activities receiving federal financial assistance; *it does not apply to decisions made by parents.*

49 Fed. Reg. 1631 (1984) (emphasis supplied.) Similarly, in the interpretative guidelines to the 504 Regulation, the Secretary stated unequivocally:

> Section 504 and the provisions of this part *are not applicable to parents (who are not recipients of Federal financial assistance).*

Id. at 1653 (emphasis supplied.) (Pet. App. 67a.)

Accordingly, the Secretary's argument (Pet. 12-18) that the terms of Section 504 clearly authorize direct federal investigation and regulation of treatment decisions involving impaired newborns is fatally flawed by her own explicit concessions that (a) parents, not health care providers, make treatment decisions on behalf of newborn infants, and (b) parents are not federal fund recipients and, thus, not within the scope of Section 504. Indeed, these concessions, made after briefing and argument in *University Hospital*, completely invalidate her own actions in that case, because there HHS was attempting to investigate and regulate directly decisions by Baby Jane Doe's parents.[17] *See* pp. 9-10, *supra.*[18]

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[17] Given the decision of the state child protective service agency not to proceed against Baby Jane Doe's parents (Pet. App. 8a), the Secretary could hardly have been arguing in *University Hospital* that she needed to investigate whether the physicians or hospital had failed to report alleged parental neglect to state authorities.

[18] In light of the Secretary's own explicit concessions about the inapplicability of a federal law triggered by receipt of federal

B. Decisions by Health Care Providers on Whether or Not to Report Suspected or Known Instances of Parental Medical Neglect to State Authorities Are Not Within the Scope of Section 504.

Given her fatal recognition in the 504 Regulation that the federal government has no authority under Section 504 to regulate parental treatment decisions, the Secretary attempts in the Regulation to do indirectly what she has conceded she cannot do directly. Section 84.55(c) of the Regulation (Pet. App. 57a) requires

> that health care providers report on a timely basis *to the state agency* circumstances which they determine to constitute *known or suspected instances of unlawful medical neglect* [by parents] of handicapped infants. (Emphasis supplied.)

Similarly, the interpretative guidelines to the 504 Regulation state (Pet. App. 67a):

> Whenever parents make a decision to withhold consent for a medically beneficial treatment or nourishment, . . . providers [who receive federal financial assistance] may not, solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable [state] procedures on reporting such incidents to the state child protective services agency or to seek judicial review [in state court].

See also Pet. 24-25. In other words, under putative authority of Section 504, the Secretary intends to investigate in individual cases whether health care providers

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funds to parental treatment decisions, Judge Winter's statement in his *University Hospital* dissent—that "denial of medical treatment to an infant because the infant is black is not legitimated by parental consent"—is clearly in error. (Pet. App. 44a.) Regardless of the race, color or creed of an infant, health care providers have no authority to operate on a child without parental consent or without a court order removing the parent as decision maker for the child, and neither Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d *et seq.*, nor Section 504 alters this fundamental rule.

are discharging their mandatory statutory duties under *state* child neglect laws to report parents to state agencies or sue parents in state courts. *See* p. 8, *supra*. But this contorted position, invalidated below, does not warrant review by this Court.

First, health care providers' decisions whether to report or prosecute parents under *state* child neglect laws are clearly outside the express terms of Section 504 because those decisions are not part of a "program or activity" receiving "federal financial assistance." The Secretary makes no showing either in her petition (*see* p. 15 n. 12) or in the preamble to the 504 Regulation that health care providers' independent, mandatory duties under *state* child neglect statutes are part of Medicaid, 42 U.S.C. § 1395 *et seq.*, Medicare, 42 U.S.C. § 1396 *et seq.*, Hill-Burton, 42 U.S.C. § 291 *et seq.*, or any other federally funded "program or activity." And she can make no such showing. Independent state law duties of health care providers are simply not part of a federal "program or activity" and therefore may not be regulated by the Secretary under Section 504. *Cf. Grove City College* v. *Bell*, 104 S. Ct. 1211 (1984) (construing narrowly "program or activity" language of Title IX of the Education Amendments of 1972, 20 U.S.C. § 1681(a)).

Second, nothing in the legislative history of Section 504 suggests that it was intended to make independent state-law duties a part of a fund recipient's federally financed "program or activity." The essence of Section 504 is to prevent recipients of federal funds—in this case federal health care funds—from denying otherwise qualified handicapped individuals "access" to the programs in which the recipient receives such funds. *Alexander* v. *Choate*, 105 S. Ct. 712, 721 (1985). *See also* S. Rep. No. 1135, 92nd Cong., 2d Sess. 49 (1972). Here, by contrast, the Secretary is trying to force health care providers to provide severely impaired infants "access" to state administrative or judicial processes so that these infants may have their parents' fitness determined by state agen-

cies or state courts under state "medical neglect" standards. *Nothing in Section 504, or its legislative history, suggests the provision was intended to provide such access to state administrative or judicial processes for determinations under state law standards.* Indeed, the Secretary does not—and cannot—cite a single shred of legislative history or a single judicial precedent contemplating or authorizing such a contorted use of Section 504, a federal civil rights statute, to enforce independent state law duties of federal fund recipients. *See* Pet. 18-21 (discussion of legislative history).

Third, while conceding that she cannot directly investigate or regulate parental treatment decisions, the Secretary—by trying to oversee the state law duties of health care providers to refer parental neglect to state agencies or courts—is indirectly using federal power to force others to review and possibly supplant the exercise of parental authority. This she simply may not do under the well-established principle that federal departments and agencies may not do indirectly what they are forbidden by statute from doing directly. *See, e.g., Sunray Mid-Continent Oil Co.* v. *FPC*, 364 U.S. 137, 151-152 (1960). The Secretary cannot regulate parental decisions under Section 504, and she cannot force health care providers to do it for her. Fourth, as discussed in the next section, Congress did not intend when it enacted Section 504 to authorize the creation of a body of "504 malpractice law" for determining whether a health care provider's decision not to report parents to state child neglect authorities in individual cases was a "reasonable medical judgment" or "unreasonable discrimination" under Section 504.[19]

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[19] The decision whether or not to report parents for alleged medical neglect is much more complicated and much more intertwined with medical practice in cases involving impaired newborns than in cases involving denial of treatment by parents on religious grounds. *See* Pet. 20, 25. In the latter case, the effects of medical treatment are crystal clear and the only bar is the religious convictions of the parents. In cases involving impaired newborns, parental decisions not to treat and providers' decisions not to re-

C. Providers' Treatment Decisions In Individual Cases Are Not Within the Scope of Section 504.

The Secretary also maintains that "not every decision by a hospital that happens to relate to the furnishing of medical treatment is perforce a bona fide medical judgment. . . ." Pet. 19. In other words, the Secretary asserts her power, under Section 504, to use officials in HHS's Office for Civil Rights, who may not even have the advice of medical consultants, to investigate and determine whether a provider's decision not to treat in an individual case, if parental consent is given, constitutes a "reasonable medical judgment." *See* 49 Fed. Reg. 1632, 1634 (1984) (504 to be applied in this context on "case-by-case" basis but no commitment to use medical consultants). But, this position is not worthy of review by this Court for several related reasons.

First, the fundamental problem with the Secretary's position is that it is based on a situation that has not occurred—and will not occur—in real life. As we already have explained, parents, not physicians and other providers, have sole legal authority to decide whether or not a child receives medical treatment. For the Secretary's hypothetical to occur, parents, in consultation with their child's physician, would have to authorize treatment for the impaired infant and the physician or hospital would then have to refuse to provide it to an "otherwise qualified" child on the basis of the child's handicap alone. Such a sequence of events is implausible on its face.

Not surprisingly, the Secretary cites no case where this has occurred.[20] In fact, nothing in its regulatory history

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port such parents are based on much more complicated medical determinations about the prognosis for the child even after treatment. *See* pp. 5-6, *supra*.

[20] As the Court of Appeals noted in *University Hospital*, "Baby Jane Doe has been treated in an evenhanded manner at least to the extent that the hospital has always been and remains willing to perform the dual, corrective surgeries if her parents would consent." (Pet. App. 39a.) *See also* pp. 27-28, *infra* ("Baby Doe of

suggests that the purpose of the voided 504 Regulation was intended to deal with this type of situation. *See* Pet. App. 66a-77a. Instead, the interpretative guidelines to the 504 Regulation make clear that it is aimed at parental "neglect" and the duty of health care providers to report such alleged "neglect." *See also* Pet. 24 (Secretary's efforts aimed at parental withholding of consent); 49 Fed. Reg. 1631 (1984) (same). Thus, the Secretary does not need the extensive regulatory regime she has created through this Regulation, which is designed to deal with known or suspected cases of parental "neglect," in order to respond instead to the nonexistent problem of physicians who refuse to treat handicapped infants after parental consent is given.

Second, when it enacted Section 504, the Congress clearly did not authorize creation of a body of "504 federal malpractice" law. But that is precisely what will occur under the Secretary's approach if HHS civil rights officials attempt to determine whether a provider's decision constituted a "reasonable medical judgment" or "unreasonable *discrimination*" under Section 504. The Secretary's glib statements that this distinction is easy to draw (Pet. 14-15, 20) and that Congress intended such line drawing are simply wrong. As the Court of Appeals stated concisely (Pet. App. 30a-31a):

> . . . in arguing that Baby Jane may have been "subjected to discrimination" the government has taken an oversimplified view of the medical decision-making process. Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent, breaks down. *Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether*

Indiana" case relied upon by Secretary did not involve physician refusal to treat).

> *a decision [by a physician] to treat, or not to treat, . . . was based on a "bona fide medical judgment", however that phrase might be defined. Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.* (Emphasis supplied.)

The Court of Appeals' succinct discussion of the legislative history of Section 504 indicates clearly that Congress did *not* intend HHS to determine when a physician's refusal to treat was reasonable or unreasonable—a question closely akin to the one asked in medical malpractice cases brought under state law. (Pet. App. 31a-35a.)[21]

Indeed, the Secretary does not cite a single passage from the legislative history indicating that Congress contemplated such an inquiry in *individual* medical cases by HHS officials.[22] And, although numerous decided cases have interpreted Section 504 in the context of "health care" programs or activities, not one,[23] however, author-

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[21] *See American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 401 (D.D.C. 1983) ("no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life").

[22] The regulatory history of Section 504, as the Court of Appeals in *University Hospital* recognized (Pet. App. 18a-20a), also refutes the Secretary's position. The original 504 regulations clearly rejected any individualized, federal right to treatment. 41 Fed. Reg. 29559 (1976). The references in the general Section 504 regulations to "health services," *see* Pet. 22, reflect a concern with access to federally funded programs and not authorization of a detailed HHS inquiry into the reasonableness or unreasonableness of a medical decision in the context of a multiply handicapped child. 41 Fed. Reg. 29567 (1976) (health services should be "accessible" and "available"). *See also Southeastern Community College* v. *Davis*, 442 U.S. 397, 411 (1979) (Secretary's interpretation of Section 504 entitled to deference only if it "honors" the language, purpose and history of the statute).

[23] Indeed, the Eighth Circuit recently dismissed a Section 504 claim alleging in part that a nursing home had discriminated

izes the kind of "504 federal malpractice" determination in individual cases contemplated by the Secretary here.

Third, sound principles of statutory construction require rejection of the Secretary's attempt to regulate health provider decisions in this area. This Court in a long line of decisions has held that "unless the Congress conveys its purpose clearly, it will not be deemed to have significantly changed the federal-state balance" in areas where the states have historically regulated. *United States* v. *Bass*, 404 U.S. 336, 349 (1971).[24] *Cf. Pennhurst State School & Hospital* v. *Halderman*, 451 U.S. 1, 17 (1981). *See also Alexander* v. *Choate*, 105 S. Ct. 712, 720 (1985) (importance of interpreting § 504 so as to keep it "within manageable bounds"). As noted above, state licensure, child neglect and other laws require that health care providers report instances of parents' medical neglect and not refuse to treat their patients unless notice is given and other treatment is available. *See* p. 4, *supra*. The Secretary's attempt to regulate, under Section 504, providers' decisions whether to treat after parental consent demonstrably intrudes on this area of historic state concern without the requisite clear expression of intent

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against a resident by failing to provide adequate medical care, concluding that "[i]n substance, this is a medical malpractice case" not cognizable under Section 504. *Hoyt* v. *St. Mary's Rehabilitation Center*, 711 F.2d 864, 867 (8th Cir. 1983). The cases that have considered Section 504 claims in the health care field have dealt with such issues as employment, *e.g.*, *United States* v. *Cabrini Medical Center*, 639 F.2d 908 (2d Cir. 1981), admission to medical schools and other medical training programs, *e.g.*, *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979), and reduction in medicaid assistance or other federally-supported medical insurance and benefits, *e.g.*, *Alexander* v. *Choate*, 105 S. Ct. 712 (1985).

[24] *See, e.g., Apex Hosiery Co.* v. *Leader*, 310 U.S. 469, 513 (1940); *FTC* v. *Bunte Brothers, Inc.*, 312 U.S. 349, 354-355 (1941). *See also United States* v. *Culbert*, 435 U.S. 371, 378 (1978); *Heublein, Inc.* v. *South Carolina Tax Commission*, 409 U.S. 275, 281-283 (1972).

by the Congress to alter the historic federal-state balance. This regulation is thus outside the scope of her authority.

* * * *

In sum, Section 504 clearly does not authorize the Secretary's attempt to investigate and regulate directly parental decisions concerning treatment of their severely impaired infants, providers' decisions about whether to refer parents to state authorities for parental neglect determinations or providers' decisions whether or not to treat if parental consent is given. Because the Court of Appeals reasonably concluded that the Secretary's regulatory approach is so demonstrably beyond the scope of her authority under Section 504, further review by this Court is not warranted.

II. THERE IS NO SUBSTANTIAL FEDERAL INTEREST IN THE VOIDED REGULATION.

The petition should also be denied because there is no substantial federal interest in the voided regulation.

A. The 1984 Child Abuse Amendments, Not the Secretary's Intrusive Regulatory Approach, Represent The Federal Interest In This Sensitive Area.

In contrast to the challenged regulatory approach adopted solely by the Secretary, the 1984 Child Abuse Amendments, as the Secretary concedes, represented an "extraordinary effort" to develop a consensus on the part of the Congress and constituted a "careful balance" between protecting severely impaired newborns and avoiding "unreasonable governmental intervention" into the practice of medicine and parental responsibilities. 50 Fed. Reg. 14879 (April 15, 1985). In contrast to the Secretary's intrusive federal regulatory approach, the 1984 Child Abuse Amendments augment existing state child protective services, rather than subverting them with a duplicative and inconsistent federal role. *Id.* at 14883 (clear intent of Congress that states use existing child protective system to carry out amendments). This considered, balanced and explicit Congressional enactment

reflects a clear Congressional intent, on policy grounds, *not* to follow the Secretary's regulatory approach in a number of important ways.

Unlike the Secretary's intrusive regulatory approach, the Congress clearly did not want a direct federal role in investigating and regulating individual cases, as the Secretary concedes in the 1984 Child Abuse Regulation, *id.* at 14885:

> The *major difference* between the section 504-based approach and that of the Child Abuse Amendments of 1984 is that the former is *implemented and enforced directly by the Federal government*, whereas the latter, within the framework of the Child Abuse Prevention and Treatment Act, relies on State implementation and enforcement regarding individual instances of child abuse and neglect. . . . (Emphasis supplied.)

As the Secretary further concedes, the legislative history of the 1984 Child Abuse Amendments clearly indicates that the Congress did not want a "new system and a new bureaucracy" created at the federal level to deal directly with the issue of treatment for impaired newborns. *Id.* at 14881.

Unlike the Secretary's intrusive regulatory approach, the Congress also did not want the creation of "*federally-prescribed medical standards* for approved treatment for specific cases." *Id.* at 14880 (emphasis supplied).[25] Such federally prescribed standards are the inevitable result of direct federal inquiry under Section 504 into the reasonableness of parental or physician decisions regarding treatment of impaired newborns.

Finally, unlike the Secretary's regulatory approach, which utilizes direct federal hotlines for the reporting of

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[25] As the Senate sponsors of the 1984 Child Abuse Amendments stated in a letter to the Secretary dated March 13, 1985, the "individuality of each case and the complexities of the medical situations associated with each case make it unwise, we believe, to establish any 'standard' form of treatment for a particular type of case." *See* 50 Fed. Reg. 14879-80 (April 15, 1985).

cases to HHS officials, the Congress in the 1984 Child Abuse Amendments did not want such federal hotlines or any regulation of the internal affairs of hospitals. As the Secretary concedes in the 1984 Child Abuse Regulation, *id.* at 14883, "matters relating to the internal affairs of hospitals are beyond the scope of this regulation." *See also id.* at 14884.

In sum, the Congress in the fall of 1984—after *University Hospital* was finally decided and after the 504 Regulation was voided—clearly addressed the question of what federal response was appropriate with respect to the tragic question of providing appropriate treatment to severely impaired newborns. It explicitly adopted a state-based approach that, in all its particulars, rejected on policy grounds the direct federal role adopted solely by the Secretary in her 504 Regulation. Given this recent and clear legislative statement by the Congress of the federal interest in this sensitive area, further review of the validity of the Secretary's intrusive administrative approach is not warranted.[26]

B. The Secretary Has Shown No Problem With the Historic State Law Framework That Warrants Direct Federal Investigation and Regulation.

After extensive hearings, the taking of written testimony and extensive deliberations, the President's Com-

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[26] Although the Secretary asserts (Pet. 27 n.22) that the "new amendments do not, either practically or legally, obviate the need for review in this case," this claim is clearly wrong. Congress did include a provision in the Amendments indicating that they did not affect any rights under Section 504. Section 127(a), 98 Stat. 1754. But if Congress had concluded that a direct federal involvement in this area—in addition to the role of parents, doctors, nurses, hospitals, and state authorities—was appropriate, it surely would have ratified the Secretary's interpretation rather than enacting new state-based legislation and creating legislative history which explicitly rejects, on policy grounds, the Secretary's direct federal approach. As a "practical" matter, the 1984 Child Abuse Amendments should take effect; if a direct federal role is necessary under Section 504, Congress can in the future provide the explicit authorization for such a role that is so clearly absent here.

mission Report (p. 209 & n.51) concluded that erroneous parental decisions about the treatment of newborns appears to be "very rare." The Report described no instances where health care providers failed to report parental neglect or refused to provide treatment to which parents had consented. Most importantly, the Secretary herself, in the preamble to the 504 Regulation, described the status of 49 cases in which HHS had investigated reports of possible "discrimination" under Section 504 with respect to impaired newborns. Although investigations had not been completed in all the cases, the Secretary concluded that "no case has resulted in a finding of discriminatory withholding of medical care." 49 Fed. Reg. 1649 (1984).

Moreover, in her petition, the Secretary does not remotely make the case that there is any problem with parental decisions or decisions by health care providers which warrants direct federal intrusion. *See* Pet. 2-3, 26.[27] Instead, the Secretary tries to mislead this Court by vaguely (and almost exclusively) citing to the "Baby Doe of Indiana" case ("Bloomington Baby Doe"), as if this case represented the kind of Section 504 "discrimination" which would be remedied by a direct HHS role. But in that situation, where a newborn with Down's Syndrome died after parents refused to authorize surgery to repair a blocked esophagus, the child's doctors initially followed the parents' decision yet the case was nevertheless referred to the hospital for further discussion. The hospital then sought judicial review of that parental non-

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[27] For example, the Secretary's citation to the preamble to the final 504 Regulation, 49 Fed. Reg. 1649 (1984), simply references the 49 cases investigated by HHS which yielded no finding of "discrimination" under Section 504. Pet. 26. Moreover, the Secretary's claim in the petition that a problem exists requiring a direct federal role is directly contradicted by her statement in the 1984 Child Abuse Regulation that "only a very small fraction of births involve any serious question of survival" and only "a fraction" of this tiny fraction would "involve even a potential allegation of medical neglect" under *state* law. 50 Fed. Reg. 14886-87 (April 15, 1985).

treatment decision. The state court decided that the parents had made a reasonable decision between treatment options. The county department of public welfare reviewed the case and decided not to challenge the judge's order further. The county prosecutor then brought a second action. And a second state court judge refused to find parental neglect.[28] In short, hospital and state authorities actively sought review of the parents' decision and two separate state court decisions supporting the parents were rendered. Accordingly, this case shows active provider and state involvement in a case of questionable parental decisionmaking—and does not remotely support the Secretary's claim that an additional level of direct federal intrusion is necessary.

Finally, not only are formal state laws and procedures functioning as intended, but the development of voluntary, hospital-based infant care review committees, *see* p. 7, *supra*, underscores that a direct federal investigatory and regulatory role is unnecessary. Indeed, as the Secretary conceded in the 1984 Child Abuse Regulation, use of these committees should reduce the need for formal *state* legal proceedings involving impaired newborns to a "[v]ery few cases." 50 Fed. Reg. 14887 (April 15, 1985). It follows *a fortiori* from this concession that there is no need for an intrusive, duplicative HHS 504 bureaucracy to investigate directly possible Section 504 violations in this sensitive area.

C. Direct Federal Investigation and Regulation In This Sensitive Area Has Caused, And Will If Reinstated Cause, Harm.

The Secretary's actions in *University Hospital* and her other 48 direct federal investigations under Section 504 perfectly illustrate the harm that is caused by a direct federal role that, in effect, duplicates and attempts to

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[28] *See In re Infant Doe*, No. GU 8204-004A (April 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind. May 27, 1982). *See also* J. Lyon, Playing God in the Nursery 21-39 (1985).

second-guess decisions made by parents, providers and state authorities. In *University Hospital*, the federal government pressed its own duplicative, harassing effort even after relevant state agencies and state courts determined that there were no grounds for state intervention. Most of the Secretary's other investigations have been equally intrusive, although none has resulted in a finding of discrimination under Section 504. 49 Fed. Reg. 1646-1649 (1984).[29] Moreover, by imposing on health care providers vague and confusing federal obligations—which are different than, Pet. 27 n.22, and may conflict with their duties under state law—the Secretary's regulatory approach has distorted medical decisionmaking. The uncertain and conflicting nature of these independent federal duties may lead to overtreatment which will only prolong the suffering of an impaired infant and which will preclude use of scarce infant intensive care units for newborns who could genuinely benefit from treatment.[30]

CONCLUSION

The interests of severely impaired newborns are protected by their parents, by infant care review committees, by the duties of health care providers under state law, by state child protective service agencies and by

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[29] Even HHS' cursory description of these investigations, *id.*, makes clear that they have resulted in invasions of family privacy, medical records and confidential medical decisionmaking, and have disrupted hospital operations and delayed ongoing treatment for impaired newborns and other patients. *See also* Affidavit of Ervin E. Nichols, M.D., Director of Practice Activities of the American College of Obstetricians and Gynecologists, ¶ 11; Affidavit of Rita G. Harper, M.D., Chief of Perinatal Medicine, North Shore University Hospital, ¶ 15; Auld Affidavit, note 6, *supra*, ¶ 18; Shapiro & Rosenberg, *The Effect of Federal Regulations Regarding Handicapped Newborns: A Case Report*, 252 J.A.M.A. 2031 (1984); Strain, *The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 New Eng. J. Med. 443 (1983).

[30] Auld Affidavit, note 6, *supra*, ¶¶ 9, 21; Affidavit of Hubert A. Ritter, M.D., clinical professor of obstetrics and gynecology, St. Louis University School of Medicine, ¶¶ 10-11.

state courts. Neither Section 504, nor any substantial federal interest, justifies the direct and intrusive federal investigation and regulation of treatment decisions involving impaired newborns advocated by the Secretary.[31]

Accordingly, for the reasons stated above, respondents AMA *et al.* respectfully request that the Secretary's petition for a writ of certiorari be denied.

Respectfully submitted,

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[31] Contrary to the Secretary's claims, Pet. 12, 27-28, the holding of the Court of Appeals in *University Hospital* and this case—which is by its terms confined to *treatment* decisions involving *severely impaired newborns*—does not control the application of Section 504 to other decisions involving impaired newborns, other treatment decisions involving non-infants, or general policies or procedures regarding federally funded health care or other programs. Nor *a fortiori* does it control any interpretation of Title VI of the Civil Rights Act of 1964. *See Consolidated Rail Corp.* v. *Darrone*, 104 S. Ct. 1248, 1254 n.13 (1984) (recognizing distinctions between Title VI and § 504). Moreover, other than the decisions in this case, no reported decisions of any court have relied upon the holding of *University Hospital*, decided more than a year ago, in any of the other contexts cited by the Secretary.

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No. 84-1529

IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, Secretary of Health and Human Services,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Petition for Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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May 25, 1985

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QUESTIONS PRESENTED

1. Whether a recent congressional enactment, supporting and reaffirming traditional state authority over matters of child abuse, precludes any finding of a significant federal question as to whether section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, authorizes the federal government to intervene in the medical treatment of infants in the absence of any expression of congressional intent to allow such conduct and in view of long-standing agency expressions of the lack of such authority.

2. Whether, under section 504, seriously-ill infants should be considered "otherwise qualified" handicapped individuals or "subject[] to discrimination" in medical treatment decisions when the statute is addressed to vocational and independent-living programs, and child treatment issues traditionally have been matters of state concern.

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

No. 84-1529

MARGARET M. HECKLER, Secretary of Health and Human Services,

Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

On Petition for Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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RESPONDENTS' BRIEF IN OPPOSITION TO PETITION FOR WRIT OF CERTIORARI

The American Hospital Association ("AHA"), the Hospital Association of New York State ("HANYS"), and Strong Memorial Hospital of the University of Rochester, the respondents herein, by their attorneys, hereby oppose the petition for a writ of certiorari to review the judgment of the United States Court of Appeals for the Second Circuit in this case.[1]

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[1] AHA has no parent or non-wholly-owned subsidiary companies; its only affiliate is the Hospital Research and Educational Trust. HANYS has no parent or non-wholly-owned subsidiary companies; its only affiliate is the Hospital Educational and Research Foundation. Strong Memorial Hospital, which has no affiliates or subsidiaries, is a division of the University of Rochester, a not-for-profit corporation organized under the laws

STATUTES AND REGULATIONS INVOLVED

1. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, provides:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disability Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulation may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

2. The Child Abuse Amendments of 1984, Pub. L. 98-457, 98 Stat. 1749, *et seq.* (1984), are reproduced, in pertinent part, in the appendix to this brief in opposition (App., *infra,* 1a-12a).

STATEMENT OF THE CASE

A. Introduction

This case involves regulations[2] concerning the medical treatment of seriously-ill infants promulgated by the United States Department of Health and Human Services

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of New York. The American Medical Association ("AMA"), also an appellee in the consolidated proceedings below, is filing a separate brief in opposition.

[2] 45 C.F.R. 84.55 and 45 C.F.R. Pt. 84, App. C, as added by 49 Fed. Reg. 1650-1654 (Jan. 12, 1984), are reproduced in the appendix to the government's petition. *See* Petition App. 53a-72a.

("DHHS" or the "Agency") under the purported authority of section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794. Because these now-invalidated regulations improperly and unlawfully intruded the federal government into the area of medical treatment decision-making, an area of traditional state concern long avoided by Congress,[3] respondents oppose the government's petition for certiorari, which seeks to revive the now-invalidated DHHS regulations.

On May 23, 1984, the Southern District of New York (Brieant, J.), relying upon the decision of the United States Court of Appeals for the Second Circuit in *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984), held that DHHS' section 504 regulations were without statutory authority and thus invalid. On June 11, 1984, the district court entered a nationwide injunction barring DHHS from further implementation or enforcement of that regulation or similar activity premised upon section 504. *AHA* v. *Heckler*, 83 Civ. 2638-CLB and consolidated case 84 Civ. 1724-CLB (Memorandum and Order) (S.D.N.Y. May 23, 1984); (Final Judgment) (S.D.N.Y. June 11, 1984).

On December 27, 1984, by unpublished order, the Second Circuit summarily affirmed the judgment of the district court. *AHA* v. *Heckler*, Nos. 84-6211, 6213 (2d Cir. Dec. 27, 1984) (*per curiam*). This petition followed.

B. The History of the Final Regulations At Issue

As enacted, section 504 contained no enforcement directives, investigative procedures or sanctions provisions. In amending the Act in 1974, Congress envisioned that the

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[3] As discussed *infra* at 10-12, Congress has enacted legislation specifically addressing the withholding of medical treatment from seriously-ill infants and has assigned to the states the oversight and enforcement responsibility under that statute. *See* Child Abuse Amendments of 1984, Pub. L. 98-457, 98 Stat. 1749, *et seq.* (1984) (App., *infra*, 1a-12a).

heads of each federal agency would promulgate comprehensive regulations to implement the Act's prohibition. *Cherry* v. *Mathews,* 419 F. Supp. 922, 924 (D.D.C. 1976), and authorities cited therein.

When DHHS (then the Department of Health, Education and Welfare ("HEW")) issued its initial section 504 regulations, which became effective in 1977, the Secretary specifically and correctly recognized that the Act provided no authority for a rule concerning an "institutionalized person's right to receive or refuse treatment." 41 Fed. Reg. 29548, 29559 (July 16, 1976).

However, in a "Notice to Health Care Providers" published on June 16, 1982 (47 Fed. Reg. 26027), DHHS attempted to reverse its long-held position and suggested for the first time that medical treatment decisions involving seriously-ill infants were within the reach of federal intervention under section 504 of the Rehabilitation Act. The notice emphasized that if a withholding of treatment were found to have been based upon handicap, federal funding would be terminated. 47 Fed. Reg. 26027.

Subsequently, on March 7, 1983, without any notice of proposed rulemaking or provision for comment, petitioner promulgated an "interim final rule" requiring hospitals to display posters in conspicuous places in every delivery, maternity and pediatric ward and in each nursery declaring that "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law." 48 Fed. Reg. 9630, effective March 22, 1983. The interim final rule further provided that "any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact the Handicapped Infant Hotline," available 24-hours-a-day to all persons who wished to make complaints, including anonymous complaints. Moreover, under the preamble to the rule, DHHS could conduct immediate investigations and make immediate referrals to the Department of

Justice for such legal action as might be found necessary. 48 Fed. Reg. 9630, 9631.

On April 6, 1983, AHA and its cohorts filed their original complaint in the instant case, seeking injunctive relief and alleging that the interim final rule was arbitrary and capricious, in excess of statutory authority, contrary to congressional intent, and impermissibly overbroad, and that its enforcement was causing irreparable harm to the very infants whom the rule purported to aid, as well as parents, doctors, and hospitals. The complaint also alleged that the interim final rule undermined public confidence in hospitals and their medical staffs. At a hearing on April 6, 1983, the district court issued a temporary restraining order prohibiting defendant "from enforcing [the interim final rule] solely to the extent that it purports to require the posting of notices upon the premises of voluntary or municipal hospitals within New York State . . . ." *AHA* v. *Heckler,* 83 Civ. 2638-CLB (Apr. 6, 1983).

On April 14, 1983, the United States District Court for the District of Columbia held that the "interim final rule . . . is invalid as an arbitrary and capricious agency action which fails to meet the standard required under the Administrative Procedure Act, 5 U.S.C. § 706(2)(A)." *American Academy of Pediatrics* v. *Heckler,* 561 F. Supp. 395, 399 (D.D.C. 1983). Although that court did not need to determine whether section 504 provided authority for the DHHS rule, it recognized the problem of extending section 504's reach "into such a sensitive area" without "evidence of [congressional] intent" and expressed the hope "that this will be clarified by further congressional action." *Id.* at 401-402.

In response to the invalidation of the interim final rule, petitioner, on July 5, 1983, proposed a somewhat revised rule, which itself was slightly modified, when, on January 12, 1984, DHHS issued the final regulation at issue in the case at bar. Section 504 of the Rehabilitation Act was

the only stated authority for all of the foregoing pronouncements.

The final regulation, which became effective on February 13, 1983, provided, *inter alia,* that hospitals must post notices stating that section 504 prohibits the withholding of "nourishment and medically beneficial treatment" from seriously-ill infants "solely on the basis of their present or anticipated impairments" and providing a confidential 24-hour telephone line for reporting "suspected noncompliance." 45 C.F.R. § 84.55(b), 49 Fed. Reg. 1651. The final regulation further required hospitals to grant DHHS officials "immediate access" to "pertinent records and facilities" when the responsible DHHS official considers such access "necessary to protect the life or health of a handicapped individual" [§ 84.55(a), 49 Fed. Reg. at 1652], and authorized DHHS to take expedited action, without prior notice, to affect compliance where "necessary to protect the life or health of a handicapped individual." § 84.55(e), 49 Fed. Reg. 1652.

Furthermore, under the aegis of state child protective services agencies, the regulation burdened hospitals with substantial new obligations to report to such agencies "suspected instances of . . . medical neglect of handicapped infants," to cooperate with such agencies' on-site investigations, and, for hospitals having infant-care review committees, to consult with the state agencies. § 84.55(c)(1)(i), (iii), and (2).

The record demonstrated that these regulatory requirements would have made it necessary for hospitals to devote their already limited and valuable staff resources to additional recordkeeping and coordination efforts. Specific individuals would have to have been designated and trained to comply with the regulation's requirements. This diversion of resources, particularly during disruptive "on-site investigations," would adversely affect patient care and the efficient administration of the hospital. *See American Acad-*

emy of Pediatrics v. *Heckler,* 561 F. Supp. at 399-401. In fact, during the time before the operation of the regulation was enjoined, such investigations, resultant from posted notices and anonymous hot lines, created morale problems and unnecessary confusion and concern within the hospitals. *Id.* In summary, the regulation imposed upon health care providers unprecedented substantial responsibilities and burdens adversely affecting patient care and hospital administration.

C. The University Hospital Decision

DHHS filed suit on November 2, 1983, in the United States District Court for the Eastern District of New York, alleging that its records-access regulation,[4] promulgated under section 504, authorized the Agency to obtain hospital medical records concerning a seriously-ill infant (known as "Baby Jane Doe"), and that the hospital had violated section 504 by refusing to grant DHHS access to records pertaining to Baby Jane Doe's treatment. The district court, in a summary judgment proceeding on that complaint, ruled against the government and held that DHHS was not entitled to the records. *United States* v. *University Hospital of the State University of New York at Stony Brook,* 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd,* 729 F.2d 144 (2d Cir. 1984). Because the appellate court decision in that case controlled disposition of the instant case below, a brief discussion of that case is worthwhile.

On February 23, 1984, the United States Court of Appeals for the Second Circuit affirmed the judgment of the Eastern District of New York and ruled that section 504 did not authorize DHHS to gain access to a hospital's medical records concerning the treatment of an infant with serious birth defects. *United States* v. *University Hospital, State University of New York at Stony Brook,* 729 F.2d 144 (2d

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[4] 45 C.F.R. § 84.61 (1982), incorporating 45 C.F.R. § 80.6(c).

Cir. 1984). The court based its decision on findings that, among other things: (1) Congress did not intend section 504 to apply to medical decisions regarding treatment of defective newborn infants; (2) Congress did not intend the federal government to involve itself in such medical decisions; (3) the regulation would impose a particularly onerous affirmative action burden on hospitals;[5] (4) although a defective newborn infant could be considered a "handicapped individual" as defined in 29 U.S.C. § 706(7)(B), such an infant could not be "otherwise qualified" or "subjected to discrimination" within the meaning of section 504;[6] and (5) without explicit language, Congress would not have intended the federal government to intrude into an area within the states' traditional police powers.

Accordingly, the court of appeals held that section 504 does not "apply to treatment decisions involving defective newborn infants," and that, "[u]ntil congress has spoken," it would be improper to permit "the type of [DHHS] investigation that has precipitated this lawsuit." 729 F.2d at 161.

D. The Filing of the Instant Case

In reaching and deciding the ultimate issue in *University Hospital,* the court of appeals expressed its awareness of the final regulation at issue in the case at bar. *See* 729 F.2d at 154. Given the categorical nature of the *University Hospital* holding, it was clear that the regulation necessarily was unlawful and that its implementation, and activities of the government related to it, should be enjoined. Notwithstanding the *University Hospital* decision, however, hospi-

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[5] The court based its affirmative action determination on this Court's admonition in *Southeastern Community College* v. *Davis,* 442 U.S. 397, 411 (1979), that there is no evidence of congressional intent that section 504 would "impose an affirmative action obligation on all recipients of federal funds." *University Hospital,* 729 F.2d at 160.

[6] *University Hospital,* 729 F.2d at 155-57.

tals still were being subjected to federal investigative activity predicated upon anonymous "hotline" calls. Therefore, on March 12, 1984, AHA, HANYS and Strong Memorial Hospital, seeking both declaratory and injunctive relief, amended their complaint to allege that the final regulation was unlawful in view of the *University Hospital* decision, and that its promulgation and implementation were violative of the Administrative Procedure Act.[7]

The district court agreed with respondents and, following the appellate court's May 17, 1984 denial of the government's petition for rehearing and suggestion for rehearing *en banc* in *University Hospital,* held, on May 23, 1984, that the final regulation was adopted without statutory authority and that it must be set aside pursuant to the Administrative Procedure Act, 5 U.S.C. § 706(2)(C). *American Hospital Association* v. *Heckler,* 83 Civ. 2638-CLB and consolidated case 84 Civ. 1724-CLB (Memorandum and Order) (S.D.N.Y. May 23, 1984). In entering its final judgment on June 11, 1984, the court also ordered injunctive relief barring any further attempt to implement or to enforce the regulation or to act in any manner contemplated under the regulation. *American Hospital Association* v. *Heckler,* 83 Civ. 2638-CLB and consolidated case 84 Civ. 1724-CLB, Final Judgment (S.D.N.Y. June 11, 1984).

The Court of Appeals summarily affirmed the district court's judgment in a *per curiam* order dated December 27, 1984. *American Hospital Ass'n, et al.* v. *Heckler,* Nos. 84-6211, 6213 (2d Cir. Dec. 27, 1984). It is that order, along with the appellate court's decision in *University Hospital,* which the government seeks to overturn.

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[7] On the same day, the American Medical Association and others filed a companion case, with essentially the same basis as the instant action. *American Medical Ass'n, et al.* v. *Heckler,* 84 Civ. 1724-CLB. The district court ordered the consolidation of the two matters with the consent of the government.

E. The Child Abuse Amendments of 1984

As is clear from the foregoing, the courts that have examined the issue of whether section 504 authorizes federal intervention in medical treatment decisions concerning seriously-ill infants have agreed that congressional action was required before the federal government could act in this field. Such action (not based upon section 504) was taken in September, 1984, seven months after the appellate court's decision in *University Hospital* and three months after the district court in the instant case enjoined DHHS from enforcing or implementing the section 504 regulations, when Congress enacted the Child Abuse Amendments of 1984 (the "Child Abuse Amendments"), Pub. L. 98-457, 98 Stat. 1749, *et seq.* (1984). This legislation, which amends the Child Abuse Prevention and Treatment Act (42 U.S.C. §§ 5101, *et seq.*), provides—in clear and specific terms—a mechanism for dealing in a comprehensive fashion with the problem which DHHS claims Congress intended to address in section 504 of the Rehabilitation Act, *i.e.*, the withholding of medically indicated treatment (including appropriate nutrition) from disabled infants with life-threatening conditions.

The Child Abuse Amendments condition the states' continued qualification for certain federal grants [*i.e.*, grants to assist the states in developing, strengthening, and carrying out their child abuse and neglect prevention and treatment programs under 42 U.S.C. § 5103(b)] upon the states' development and implementation of procedures or programs within their child protective services systems:

> to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law,

> for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Pub. L. No. 98-457, § 122(3), 98 Stat. 1752-53 (App., *infra*, 7a-8a), *amending* 42 U.S.C. § 5103(b)(2).

The Child Abuse Amendments also require the Secretary of DHHS to promulgate regulations implementing the requirements of the provision described above [42 U.S.C. § 5103(b)(2)(K) (as added by Section 122(3) of Pub. L. No. 98-457)], as well as to promulgate model guidelines to encourage hospitals to establish committees:

> which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions.

Pub. L. No. 98-457, § 124, 98 Stat. 1754 (App., *infra*, 10a).

In addition to delineating specific roles for the state and federal governments to address the withholding of medically indicated treatment from disabled infants, the Child Abuse Amendments define such conduct with considerable exactitude:

> the term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical

> judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id. at § 121(3) (98 Stat. 1752) (App., *infra*, 6a-7a), *amending* 42 U.S.C. § 5102.

Relevant provisions of the Child Abuse Amendments thus address the issue of medical treatment decisions concerning seriously-ill infants in a detailed and comprehensive manner which recognizes: (a) the *inappropriateness* of requiring the provision of treatment in certain statutorally-specified circumstances; (b) the primacy of the judgments of parents and treating physicians; and (c) the traditional enforcement and oversight role of the states where abuse is suspected.

SUMMARY OF ARGUMENT

Although Congress was aware of the legal challenges to DHHS' section 504-based regulation authorizing federal intervention in medical treatment decisions concerning seriously-ill infants, instead of amending section 504 to make clear an "intent" supporting that regulation, Congress enacted the Child Abuse Amendments of 1984. In doing so, Congress recognized and endorsed the traditional role of the states in addressing such treatment decisions. By enacting the comprehensive and carefully crafted Child Abuse Amendments, Congress made a clear choice of the approach it intended to take as to medical treatment of infants. DHHS now petitions this Court to disregard that congressional choice and seeks to have the Court overturn the appellate court's holding in *University Hospital* that Congress did not intend section 504 to authorize federal government

intervention in medical treatment decisions concerning seriously-ill infants. The enactment of the Child Abuse Amendments, however, has negated the existence of a substantial issue for this Court's resolution, and denial of the government's petition is, therefore, appropriate.

Furthermore, even if Congress had not enacted the Child Abuse Amendments, it is apparent that the *University Hospital* decision was correctly decided: seriously-ill infants are not, within the meaning of section 504, "otherwise qualified handicapped individuals" who may be "subjected to discrimination" with regard to federally-assisted "programs or activities." Neither the statute nor the legislative history supports the government's interpretation of the statute which: (1) is contrary to the Agency's previously long-held interpretation of the statute; (2) is based on a faulty analogy to racial discrimination prohibited under Title VI of the Civil Rights Act; (3) reads the term "otherwise qualified" out of the statute; (4) fails to identify a federally-assisted program or activity that could engage in discrimination prohibited by section 504; and (5) is otherwise illogical. Accordingly, the government's petition for writ of certiorari should be denied.

REASONS FOR DENYING THE GOVERNMENT'S PETITION

A. Because Congress, Recognizing That Legislative Authorization Must Precede Federal Intervention In Medical Treatment Decisions Involving Seriously-Ill Infants and That a Valid Legislative Approach Depended Upon the Primacy of State Authority, Enacted The Child Abuse Amendments, There Is No Significant Question Of Federal Law For This Court To Decide.

Congress' enactment of the Child Abuse Amendments obviates any possibility that the issues presented by DHHS raise "special and important reasons" for granting certiorari as required by Rule 17 of the Supreme Court. Because Congress' intent was clearly expressed in the Child

Abuse Amendments, the correctness of the opinion below does not constitute an "important question of federal law" worthy of this Court's consideration. S. Ct. R. 17(c). Accordingly, as a matter of policy, this Court should exercise its discretion to deny certiorari in this case. *See Rice* v. *Sioux City Memorial Park Cemetery, Inc.*, 349 U.S. 70, 74 (1955). (" 'special and important reasons' imply a reach to a problem beyond the academic or the episodic").[8]

When it enacted the Child Abuse Amendments, Congress was fully aware of the courts' expressed refusal to hold that section 504 authorized federal intervention in medical treatment decisions concerning seriously-ill infants absent a clear expression of congressional intent. *See* S. Rep. No. 246, 98 Cong., 2d Sess. 5-8 (1984). Rather than attempting to amend section 504 to "clarify" its intent in that regard, however, Congress, in the Child Abuse Amendments, recognized its appropriate role and, therefore, revalidated and amplified the states' traditional function in dealing with such issues.

The role specified for the federal government in the Child Abuse Amendments was limited to promulgating regulations to ensure that the states fulfilled their statutory responsibilities and guidelines for hospitals to deal with the treatment of seriously-ill infants. Pursuant to Congress' direction, DHHS, on April 15, 1985, published its final rule implementing the Child Abuse Amendments. 45 C.F.R. Part 1340, as added by 50 Fed. Reg. 14887-92 (April 15, 1985). In its preface to the final rule, DHHS conceded that the Child Abuse Amendments reflect Congress' considered choice of the most desirable and workable approach to the

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[8] In *Rice* v. *Sioux City Memorial Cemetery, Inc.*, 349 U.S. 70 (1955), this Court dismissed a writ of certiorari because, although a federal question had been raised, a new state statute prohibiting the action in question would afford a remedy to those in situations similar to that of the petitioner, thereby eliminating the existence of an issue of "public importance." *Id.* at 77. *See also United States* v. *Alaska S.S. Co.*, 253 U.S. 113, 115-16 (1920); *Berry* v. *Davis*, 242 U.S. 468, 469 (1917).

issue of the withholding of medical treatment from seriously-ill infants.

> [T]his legislation was the product of an extraordinary effort on the part of several Senators and Congressmen and representatives of a wide range of medical, right-to-life and disability organizations to forge a substantial consensus on an effective and workable program to assure the provision of appropriate medical care to disabled infants.
>
> • • • •
>
> It is clear that the legislation represented a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable government intervention into the practice of medicine and parental responsibilities.

50 Fed. Reg. at 14879.

DHHS also recognized the clear congressional preference for the states—rather than the federal government—to take the lead role. Thus, the Agency emphasized that primary among "several key points [that] emerge from the statute and the legislative history" is that:

> [P]rocedural requirements should build upon existing mechanisms at the state level, rather than creating a new system and a new bureaucracy to respond to reports of known or suspected instances of the withholding of medically indicated treatment from infants with life-threatening conditions.

50 Fed. Reg. at 14881.[9] The Agency further recognized that the states' role rendered unnecessary a confidential 24-hour

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[9] In contrast to the language and legislative history of the Child Abuse Amendments, which, as DHHS concedes, demonstrate a clear congressional intent to "build upon eixsting mechanisms at the state level," 50 Fed. Reg. at 14811, the language and legislative history of section 504 contains no indication that Congress intended that statute to address in *any* way the withholding of treatment from seriously-ill infants. And although § 127(a) of the Child Abuse Amendments (98 Stat. 1754) (App. 11a) provides that the Amendments are not "intended to affect any right or protection under section 504," even the government does not claim (and it could not) that this provision reveals a congressional intent to address infant treatment decisions in section 504.

federal telephone line for reporting the suspected withholding of treatment from seriously-ill infants, although such hot-lines were in fact specified in DHHS' invalidated section 504 regulation. *See* 45 C.F.R. § 84.55(b), 49 Fed. Reg. 1651. Thus, as DHHS stated in its preface to its April 15, 1985 regulations:

> Because the Act so clearly places responsibility for implementation on State CPS [Child Protective Service] agencies, the Department [DHHS] does not see a need to establish a Federal hot-line for reporting suspected instances of medical neglect as requested by some commenters. Such a federal reporting system would not be the most effective in assuring the most prompt reporting to State or local CPS agencies.

50 Fed. Reg. at 14884.

Despite DHHS' recognition that the Child Abuse Amendments represent Congress' considered and carefully-crafted decision concerning the proper allocation of authority for dealing with the treatment of seriously-ill infants, DHHS now maintains that an important federal question exists. The government wants this Court to determine that in section 504, Congress implicitly authorized DHHS to assume the role assigned to the states in the Child Abuse Amendments. To the contrary, Congress has removed the necessity for this Court to consider the potential scope of section 504 by considering the relevant issues and enacting an appropriate statutory scheme pursuant to the Child Abuse Amendments.[10] Thus, there are no "special or important reasons" for the Court to consider the issues presented by

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[10] Because Congress has determined the method for best dealing with the treatment of seriously-ill infants, DHHS' petition is analagous to a request for resolution of a political question, which this Court has long held it will not decide. *See Colegrove* v. *Miller*, 307 U.S. 433 (1939) (questions that are "appropriate for the political departments of the Government . . . are essentially political and not justiciable"). *See also Mathews* v. *Diaz*, 426 U.S. 67, 81 (1976) (courts should refrain from inhibiting "the flexibility of the political branches of government to respond to the changing world conditions").

DHHS. *Rice*, 349 U.S. at 74.

B. Section 504 Does Not Provide Authority for the Federal Government to Supersede the Traditional Role of the States in Dealing With the Medical Treatment Of Seriously-Ill Infants.

In addition to the substantial policy considerations requiring denial of the government's petition, such denial also is required by long-established precedent precluding federal entry into a field traditionally occupied by the states in the absence of a clear congressional mandate.

In *Apex Hosiery Co.* v. *Leader*, 310 U.S. 469 (1940), the Court emphasized that:

> The maintenance in our federal system of a proper distribution between state and national governments of policy authority and of remedies private and public for public wrongs is of far-reaching importance. An intention to disturb the balance is not lightly to be imputed to Congress.

310 U.S. at 513 (1940). *See also Jones* v. *Rath Packing Co.*, 430 U.S. 519, 525 (1977), *quoting United States* v. *Bass*, 404 U.S. 336, 349 (1971). Accordingly, this Court "in construing legislation . . . has disfavored in-roads by implication" upon the states' traditional police powers. *Palmer* v. *Commonwealth of Massachusetts*, 308 U.S. 79, 84 (1939).

Applying these principles to a Federal Trade Commission attempt to enforce the Trade Commission Act (15 U.S.C. §§ 44, 45(a)) vis-a-vis purely *intra*state commerce, the Court held that the Commission's interpretation of the Act "would . . . give a federal agency pervasive control over . . . matters heretofore traditionally left to . . . local law," and that "[a]n inroad . . . of such far-reaching import ought to await a clearer mandate from Congress." *FTC* v. *Bunte Bros., Inc.*, 312 U.S. 349, 354-55 (1941). With regard to medical treatment decisions concerning seriously-ill infants, Congress has provided in the Child Abuse

Amendments a clear mandate recognizing and amplifying the states' exercise of their traditional authority in the area of child abuse and neglect. It is thus apparent that DHSS' section 504 regulation constitutes an improper attempt by the federal government to enter a "police power" field long occupied exclusively by the states. Indeed, Congress recognized as much when it enacted the Child Abuse Amendments rather than amending section 504 specifically to authorize the role which DHHS claims under that statute.

The government essentially takes the position that section 504 authorizes it to investigate and intervene in treatment decisions concerning seriously-ill infants regardless of whether the relevant state agency already has taken an active role in such cases. While "state statutes and regulations may be superseded by validly enacted regulations of federal agencies . . . ," *Katharine Gibbs School, Inc.* v. *FTC*, 612 F.2d 658, 667 (2d Cir. 1979), it is also the case that "[w]here the field which Congress is said to have preempted has been traditionally occupied by the State, . . . 'we start with the assumption that the historic police powers of the States were not to be superseded unless that was the clear and manifest purpose of Congress.'" *Jones* v. *Rath Packing Co.*, 430 U.S. at 525, *quoting Rice* v. *Santa Fe Elevator Corp.*, 331 U.S. 218, 230 (1947) (other citations omitted).

There can be no dispute that the states traditionally have occupied the field of protection of children against abuse. For example, the District Court in *University Hospital* found as a matter of fact that the New York State Child Protective Service was constituted for this very reason, and indeed heavily relied upon its finding that Baby Jane Doe's parents had made an appropriate medical decision. *United States* v. *University Hospital*, 575 F. Supp. at 611, 615.[11] Additionally, most states have enacted a panoply of

[11] Virtually all states have similar child protective services programs.

statutes that prohibit hospitals and physicians from disclosing information gained during treatment without the consent of the patient.[12]

With regard to the necessary confidentiality of medical records, as well as the broader question of the medical treatment of seriously-ill infants, it is apparent that Congress, in enacting section 504, did not intend even to *enter* the field, much less to occupy this area of traditional state concern. *See infra* at — - —. Accordingly, and particularly in view of the Child Abuse Amendments' deference to the states' role, section 504 provides no authority for DHHS to investigate or intervene in treatment decisions concerning such infants.

C. The Court of Appeals Decided The *University Hospital* Case Correctly Because The Government Clearly Does Not Have Authority Under Section 504 To Regulate Or To Intervene As To Medical Treatment Decisions Concerning Infants With Serious Birth Defects.

1. The Plain Meaning of Section 504 Was Properly Interpreted in the *University Hospital* Decision Because the Language of That Statute on its Face Does not Apply to Treatment of Seriously-Ill Infants.

This Court has long held that under the "plain meaning rule," interpretation of a statute "must, in the first instance, be sought in the language in which the act is found, and if that is plain, . . . the sole function of the courts is to enforce it according to its terms." *Caminetti* v. *United States,* 242 U.S. 470, 485 (1917). *See also American Tobacco Co.* v. *Patterson,* 456 U.S. 63 (1982); *Southeastern Community College* v. *Davis,* 442 U.S. 397 (1979). Furthermore, with specific regard to section 504 of the Reha-

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[12] *See, e.g.:* New York statutes: CPLR § 4504(a); Education Law § 6509(9); Public Health Law § 2803-c(3)(f) and § 2805-g(3); 8 NYCRR 29.1(b)(8), 10 NYCRR 405.25(a)(9) and 10 NYCRR 405.1026(a).

bilitation Act, this Court, in *Alexander* v. *Choate*, —— U.S. ——, 105 S. Ct. 712, 720 (1985), recently cautioned against stretching interpretations of section 504 beyond "manageable bounds."

Contrary to any reasonable concept of statutory construction, however, the government is in effect requesting this Court to ignore two specific requirements of section 504: (1) that the statute prohibits discrimination against an "otherwise qualified" handicapped individual and (2) that such discrimination must flow from, or be related to, a "program or activity receiving federal financial assistance." 29 U.S.C. § 794. Such an interpretation of section 504 is untenable because the language of that statute clearly sets forth that *only* an "otherwise qualified" handicapped individual may be subjected to discrimination forbidden under that statute, and *only* as to a "program or activity receiving federal financial assistance." 29 U.S.C. § 794. The government's claim that section 504 authorizes a federal role with regard to the treatment of seriously-ill infants rests fundamentally upon a studied evasion of those statutory requirements. And although the government attempts to support its position with an untenable analogy to racial discrimination and various mischaracterizations of the *University Hospital* decision, scrutiny of the government's analysis reveals it to be insupportable.

a. Contrary to the Government's Interpretation, Seriously-Ill Infants Are Not "Otherwise Qualified" Within the Plain Meaning of the Statute.

In attacking the *University Hospital* decision, the government misconceives the thrust of that decision and the facts and circumstances discussed therein. For example, despite the absence of statutory language suggesting *any* applicability of section 504 to medical treatment decisions involving seriously-ill infants, the government blithely

states that "the language of section 504 *clearly prohibits* a [federally assisted] hospital program from withholding nourishment or medically indicated treatment from a handicapped infant solely by reason of his handicap." Petition at 13 (emphasis supplied). Not only is such a prohibition *not* clear from the statutory language, but the government's omission of the term "otherwise qualified" from its description of what section 504 "clearly prohibits" reveals that the government is attempting to avoid the consequences of that statutory prerequisite.

In place of "otherwise qualified," the government apparently would substitute a phrase such as "needing or capable of benefitting from an identifiable course of medical treatment." *See* Petition at 14-15. The government thus defines the term "otherwise qualified handicapped individual" far differently than did this Court in *Southeastern Community College* v. *Davis,* where the Court stated the term means "one who is able to meet all of a program's requirements in spite of his handicap." 442 U.S. at 406.

In fact, the government's reading of the term stretches it so far beyond anything Congress contemplated as to read the term out of the statute. If, as the government observes, "one need not possess any special qualifications to benefit from . . . nourishment [or] medical treatment" (Petition at 15), such nourishment and treatment clearly are not the kind of "programs or activities" as to which Congress prohibited discrimination against *otherwise qualified* individuals. In other words, if Congress did not intend or contemplate that medical treatment decisions would be considered "programs or activities" for which a handicapped individual might or might not be "otherwise qualified," the term "otherwise qualified" cannot be applied in the context of such treatment decisions without destroying the plain meaning of that term. Accordingly, the government's reading of "otherwise qualified" violates the fundamental principles of statutory construction that statutes

should not be be construed to produce absurd results or to prevent giving effect to each term thereof. *See Griffin* v. *Oceanic Contractors, Inc.*, —— U.S. ——, 102 S. Ct. 3245, 3252 (1982); *Colautti* v. *Franklin*, 439 U.S. 379, 392 (1979).

Although, as discussed below, the appellate court in *University Hospital* examined congressional intent concerning section 504, it further emphasized the practical problems inherent in the government's "superficial[ly] logic[al]" position, when the court rejected the government's argument that seriously-ill infants can be "otherwise qualified" and "subjected to discrimination" within the meaning of section 504. *Id.* at 156. Thus, as the court stated, "the government's view of 'otherwise qualified' is divorced from the statutory language," as revealed by the cases interpreting the statute, and from the "plain, obvious and rational meaning" of the term, as shown by the fact that:

> In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents.

729 F.2d at 156-57.

As the appellate court correctly observed, the Rehabilitation Act, rather than addressing treatment decisions, was designed to increase the participation of handicapped persons in vocational, employment, educational and similar federally-assisted programs and to prohibit discrimination that would deny such individuals access to or participation in such programs. *Id.* at 155-59.[13] This Court recently echoed that analysis in *Alexander* v. *Choate*, when it

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[13] As the Act's declaration of purpose makes clear:

> The purpose of this chapter is to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living.

29 U.S.C. § 701.

stressed that section 504 was part of "major vocational-rehabilitation legislation" (105 S. Ct. at 718 n. 13) having as some of its paramount goals the elimination of architectural barriers, barriers to access to public transportation, special education or rehabilitation services, and discriminatory job qualification procedures. *Id.* at 719. This Court did *not* include in its enumeration of the Rehabilitation Act's goals the prevention of the withholding of medical treatment from seriously-ill infants, and it is apparent that the statute's plain meaning does not encompass the role that DHHS claims for itself.

b. There Are No Federally-Assisted Programs or Activities Which Could Engage in Discrimination Prohibited by the Plain Meaning of Section 504.

Even if it is assumed *arguendo* that seriously-ill infants can be "otherwise qualified," there exists no federally-assisted "program or activity" which could discriminate against such infants within the meaning of section 504. As the government concedes, neither the court of appeals in *University Hospital* nor the courts below in the instant case resolved the issues concerning the nature or identity of the "program or activity receiving federal financial assistance," although the government suggests that the *sources* of such federal assistance would include Medicare and Medicaid funds as well as "Hill-Burton and other construction funds." *See* Petition at 15-16, n. 12. It is apparent, however, that there is *no* federally-assisted program or activity whose conduct with regard to treatment decisions concerning seriously-ill infants could constitute discrimination prohibited under section 504, and that the statute, therefore, cannot apply to such treatment decisions.

Even if *all* of a hospital's programs and activities were deemed to be federally-assisted,[14] because hospitals are

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[14] Although there is substantial doubt that hospitals are recipients of federal financial assistance by virtue of their receipt of Medicare and Medicaid payments (*see Cook* v. *Budget Rent-A-Car Corp.*, 502 F. Supp.

not empowered to *make* treatment decisions, a hospital simply could not engage in discrimination in such decisions. In addition, despite the government's claim that section 504 requires hospitals to initiate steps to override parental decisions, hospitals likewise lack legal authority to require that parents choose a different course of treatment than the one they have determined to pursue. On the contrary, hospitals always are prepared to render those services which parents, in consultation with the treating physicians, determine to be medically necessary.

Certainly, the government does not, and could not, contend that parents are federally-assisted programs or activities,[15] and the federal government would have no authority under section 504 to take any action, remedial or punitive, with regard to parental treatment decisions.

The government's attempt to suggest that "nourishment" or "corrective surgery" constitutes federally-assisted programs or activities for purposes of section 504 (Petition at 4-15) is similarly specious. Aside from the fact that parents, rather than hospitals, are the parties who decide whether such nourishment or treatment will be furnished to a seriously-ill infant, the government's position

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494 (S.D.N.Y. 1980)), the appellate court in *University Hospital* found it unnecessary to decide (although it is assumed) that such payments do constitute federal assistance to recipient hospitals. 729 F.2d at 151. In addition, it could not be said that the Medicare and Medicaid legislation provided hospitals unambiguous notice that, as a condition of receiving such payments, they would be subject to DHHS' claimed authority to investigate and intervene in medical treatment decisions concerning seriously-ill infants. *See Pennhurst State School and Hospital* v. *Halderman*, 451 U.S. 1, 17 (1981). While the AHA Respondents do not abandon their arguments that the DHHS section 504 regulations are invalid on these grounds, as well as for all the reasons addressed in this brief in opposition, the AHA Respondents will not burden this brief with a discussion of these grounds not addressed by the court in *University Hospital*.

[15] Indeed, the Secretary has conceded that parents are not recipients of federal financial assistance. 49 Fed. Reg. at 1653.

that there are no "qualifications" necessary for an individual to benefit from such nourishment or treatment makes it clear that they are not the kinds of "programs or activities" as to which Congress prohibited discrimination in section 504. *See supra* at 21-22.

In view of the government's avoidance of the statutory requirements that individuals be "otherwise qualified" and that the alleged discrimination occur vis-a-vis a federally-assisted "program or activity," it is apparent that it cannot establish that section 504 has any application to medical treatment decisions concerning seriously-ill infants.

2. Congress Did Not Intend Section 504 to Apply to Treatment Decisions Involving Seriously-Ill Infants.

Because the Court of Appeals in *University Hospital* determined that the language of section 504 does not make "crystal clear its intended scope,"[16] and that it does not "plainly apply"[17] to medical treatment decisions involving seriously-ill infants, it looked to congressional intent to determine the scope of the statute's applicability. In doing so, the court of appeals complied with this Court's admonition that "[w]here . . . resolution of a question of federal law turns on a statute and the intention of Congress, we first look to the statutory language and then to the legislative history if the statutory language is unclear." *Blum* v. *Stenson*, —— U.S. ——, 104 S. Ct. 1541, 1548 (1984). *See also United States* v. *Turkette*, 452 U.S. 576, 580 (1981); *Philbrook* v. *Glodgett*, 421 U.S. 707, 713 (1975).

The appellate court's *University Hospital* decision turns primarily on the issue of congressional intent, which the court determined after an exhaustive review of the legislative history. 729 F.2d at 157-61. As the court summarized,

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[16] 729 F.2d at 161, *quoting Allen* v. *State Board of Elections*, 393 U.S. 544, 570 (1969).

[17] 729 F.2d at 159, *quoting United States* v. *Jones*, 607 F.2d 269, 273 (9th Cir. 1979), *cert. denied*, 444 U.S. 1085 (1980), and *citing* other cases.

"[o]ur review of the legislative history has shown that congress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants . . . ." *Id.* at 161 (citation omitted).

In concluding that Congress did not intend section 504 to authorize governmental involvement in medical treatment decisions concerning such infants, the court looked not only to the absence of expression of such intent in congressional deliberations concerning the Rehabilitation Act (729 F.2d at 157-58), but also to the "post-enactment legislative history" (including congressional oversight hearings) (*id.* at 159), and to *other* congressional enactments which, as the court observed, express the will of Congress that "determinations regarding the quality and appropriateness of medical treatment should not be undertaken by federal officials." *Id.* at 160 (citations omitted). As the court made clear, it could not presume, "[i]n view of this consistent congressional policy *against* the involvement of federal personnel in medical treatment decisions . . . that congress intended [by enacting section 504] to repeal its earlier announcements in the absence of clear evidence of congressional intent to do so." *Id.* (citations omitted, emphasis supplied). Accordingly, the court emphasized that, contrary to "the government's new interpretation, . . . neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." *Id., quoting Southeastern Community College,* 442 U.S. at 411 (other citations omitted).

Equally significantly, stressing the virtual impossibility of determining that a medical decision concerning a handicapped condition is or is not discriminatory when that condition is (or is related to) the subject of the decision, the court of appeals highlighted the illogicality of the govern-

ment's attempt to analogize such decisions to those involving racial discrimination. 729 F.2d at 157. And as this Court recently warned, although section 504 is patterned after the anti-discrimination provision of Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d, *et seq.*, "too facile an assimilation of Title VI law to §504 must be resisted." *Alexander* v. *Choate,* 105 S. Ct. at 716-17 n. 7. Because Congress perceived discrimination against the handicapped "to be most often the product, not of invidious animus, but . . . of benign neglect" (*id.* at 718), the government's attempt to read Title VI and section 504 *in pari materia* is misguided. *Id.* at 717, n. 11.

Thus, the appellate court concluded that neither the statute's plain meaning nor its legislative history support the government's contention that section 504 authorizes federal government intervention in medical treatment decisions concerning seriously-ill infants. The government's petition for certiorari should, therefore, be denied.

3. The *University Hospital* Court Properly Determined That DHHS' Current Position Concerning the Applicability of Section 504 Is Not Entitled to Deference.

While courts often defer to an agency's interpretation of the statute it administers, "[i]n order for an agency interpretation to be granted deference, it must be consistent with the congressional purpose." *Morton* v. *Ruiz,* 415 U.S. 199, 237 (1974) (citations omitted). In addition, to be entitled to any weight, such agency interpretations must also be *consistently held. United States* v. *National Association of Securities Dealers, Inc.,* 422 U.S. 694, 718 (1975); *Morton* v. *Ruiz,* 415 U.S. at 237; *Trafficante* v. *Metropolitan Life Insurance Co.,* 409 U.S. 205, 210 (1972).

Because, as described above, the government's position is supported by neither the plain meaning of section 504 nor congressional intent (as revealed by the legislative history of section 504 and the subsequent enactment of

the Child Abuse Amendments), the government's recently-announced view that section 504 permits intervention in infant treatment decisions lacks consistency with congressional purpose, and therefore must be rejected. *Morton* v. *Ruiz,* 415 U.S. at 237. *See also Southeastern Community College,* 442 U.S. at 411.

Further, DHHS' inconsistent interpretation of section 504 precludes deference to the Agency's current interpretation. In 1976, the Secretary (of what was then HEW) recognized that section 504 provided no authority for a rule concerning an "institutionalized person's right to receive or refuse treatment." 41 Fed. Reg. 29548, 29559 (July 16, 1976). Then, beginning in 1982 DHHS attempted to reverse its long-held position regarding the inapplicability of section 504 to the treatment of seriously-ill infants. *See supra* at 4-7. Against this background, the court of appeals in *University Hospital* properly refused to defer to DHHS' position, recognizing that the Agency's "current view of the scope of the statute is flatly at odds with the position originally taken by HEW." 729 F.2d at 152. *See also id.* at 152-54.

Not only is the Agency's current interpretation of section 504 inconsistent with its original position, but it is also inconsistent with positions that it has stated in other contexts. For example, based on its unsupported claim that Congress intended section 504 to apply to medical treatment decisions concerning seriously-ill infants, as well as upon a rigid analogy to racial discrimination, the government insists that:

> [Because] a federally-assisted hospital would not be free under Title VI to decline to perform surgery to remove an intestinal obstruction in an infant because of his race, . . . [i]t is equally unlawful under Section 504 for the hospital to decline to perform the same surgery on an infant because of his handicap . . . .

Petition at 19. DHHS, however, has elsewhere taken the position that *no* violation of section 504 would arise in regard to the failure to treat an infant so seriously ill that such treatment is "futile" or would do no more than "temporarily prolong the act of dying." 49 Fed. Reg. at 1653. In essence, then, the government contends that when a seriously-ill infant reaches a certain level of defect, the asserted protection of section 504 no longer applies, and that it is for the *federal government* to determine when this point has been reached. However, neither the language of section 504 nor its legislative history provides any support for the government's position.

Similarly, although the Secretary has made it clear, in Appendix C to the final rule ("Guidelines Relating to Health Care for Handicapped Infants"), 49 Fed. Reg. at 1653, that "[s]ection 504 and the provisions of this part [*i.e.*, the final rule] are not applicable to parents," *id.*, the government in its petition contends that it has authority under section 504 to require a hospital to "initiate steps to override" certain parental decisions. Petition at 25.[18]

Because DHHS' current interpretation of section 504 is inconsistent with congressional purpose and with other Agency positions, the court in *University Hospital* properly refused to defer to the Agency's current interpretation.

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[18] The government's contention (Petition at 24-25) that no "affirmative action" obligation would be imposed by requiring hospitals to "initiate steps" (including litigation if necessary) to override parental decisions is simply inaccurate. As DHHS emphasized in the preamble to its final rule, the Agency believes that section 504 requires a hospital "to seek judicial review itself, so as to trigger the system provided by State law to determine whether [a] parental decision should be honored." 49 Fed. Reg. at 1631. In addition, DHHS suggested that hospitals should condition physicians' staff privileges upon the doctors' agreement to abide by the requirements of section 504. *Id.* at 1637. Such requirements clearly extend hospitals' responsibilities beyond any obligation the hospitals may have not to discriminate.

CONCLUSION

Contrary to the government's contentions, the appellate court in *University Hospital* correctly decided that section 504 was not intended to address medical treatment decisions concerning infants with birth defects. In any event, to the extent there is a cognizable issue with regard to such treatment decisions, Congress has chosen to address any possible issues related to such decisions not in section 504, but rather through the Child Abuse Amendments, which recognize and expand the traditional role of the states. Finally, in seeking, by regulation and otherwise, to intervene in medical treatment decisions regarding seriously-ill infants and to gain access to medical records concerning such infants, the government is proceeding contrary to well-established principles, and in the absence of legitimate, unambiguous, and narrowly-drawn statutory or regulatory authority.

Accordingly, for all the reasons set forth above, the AHA Respondents respectfully urge this Court to deny the government's petition for writ of certiorari.

Respectfully submitted,

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May 25, 1985

APPENDIX

APPENDIX

PUBLIC LAW 98-457 [H.R. 1904]; October 9, 1984

CHILD ABUSE AMENDMENTS OF 1984

An Act to extend and improve provisions of laws relating to child abuse and neglect and adoption, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Child Abuse Amendments of 1984".

TITLE I—AMENDMENTS TO CHILD ABUSE PREVENTION AND TREATMENT ACT

PART A—PROGRAM IMPROVEMENTS

The National Center on Child Abuse and Neglect

SEC. 101. (a) Section 2(a) of the Child Abuse Prevention and Treatment Act (42 U.S.C. 5101(a)) (hereinafter in this title referred to as "the Act") is amended by striking out "Health, Education, and Welfare" and inserting in lieu thereof "Health and Human Services".

(b) Clauses (6) and (7) of section 2(b) of the Act are amended to read as follows:

"(6) study and investigate the national incidence of child abuse and neglect and make findings about any relationship between nonpayment of child support and between various other factors and child abuse and neglect, and the extent to which incidents of child abuse and neglect are increasing in number and severity, and, within two years after the date of the enactment of the Child Abuse Amendments of 1984, submit such findings to the appropriate Committees of the Congress together with such recommendations for admin-

istrative and legislative changes as are appropriate; and

"(7) in consultation with the Advisory Board on Child Abuse and Neglect, annually prepare reports on efforts during the preceding two-year period to bring about coordination of the goals, objectives, and activities of agencies and organizations which have responsibilities for programs and activities related to child abuse and neglect, and, not later than March 1, 1985, and March 1 of each second year thereafter, submit such a report to the appropriate Committees of the Congress.".

(c) Section 2(c) of the Act is amended by striking out "The Secretary may carry out his functions under subsection (b) of this section" and inserting in lieu thereof "The functions of the Secretary under subsection (b) of this section may be carried out".

(d) Section 2 of the Act is further amended by inserting after subsection (d) the following new subsection:

"(e) No funds appropriated under this Act for any grant or contract may be used for any purpose other than that for which such funds were specifically authorized.".

Definitions

SEC. 102. Section 3 of the Act is amended—

(1) by inserting "(including any employee of a residential facility or any staff person providing out-of-home care)" after "by a person";

(2) by striking out the period at the end thereof and inserting in lieu thereof a semicolon; and

(3) by adding at the end thereof the following new clause:

"(2)(A) the term "sexual abuse" includes—

"(i) the employment, use, persuasion, inducement, enticement, or coercion of any child to engage in, or having a child assist any other person to engage in, any sexually explicit conduct (or any simulation of such conduct) for the purpose of producing any visual depiction of such conduct, or

"(ii) the rape, molestation, prostitution, or other such form of sexual exploitation of children, or incest with children,

under circumstances which indicate that the child's health or welfare is harmed or threatened thereby, as determined in accordance with regulations prescribed by the Secretary; and

"(B) for the purpose of this clause, the term 'child' or 'children' means any individual who has not or individuals who have not attained the age of eighteen.".

Demonstration or Service Programs and Projects

SEC. 103. (a) Section 4(b)(2)(E) of the Act is amended by striking out "his" and inserting in lieu thereof "and the child's".

(b) Section 4(b)(3) of the Act is amended to read as follows:

"(3)(A) Subject to subparagraph (B) of this paragraph, any State which on the date of enactment of the Child Abuse Amendments of 1984 does not qualify for assistance under this subsection may be granted a waiver of any requirement under paragraph (2) of this subsection—

"(i) for a period of not more than one year, if the Secretary makes a finding that such State is making a good-faith effort to comply with any such requirement, and for a second one-year period if the Secretary makes a finding that such State is making substantial progress to achieve such compliance; or

"(ii) for a nonrenewable period of not more than two years in the case of a State the legislature of which meets only biennially, if the Secretary makes a finding that such State is making a good-faith effort to comply with any such requirement.

"(B) No waiver under subparagraph (A) may apply to any requirement under paragraph (2)(K) of this subsection.".

(c) Section 4 of the Act is further amended—

(1) by redesignating subsection (e) as subsection (f); and

(2) by inserting after subsection (d) the following new subsection:

"(e) The Secretary, in consultation with the Advisory Board on Child Abuse and Neglect, shall ensure that a proportionate share of assistance under this Act is available for activities related to the prevention of child abuse and neglect.".

Authorization of Appropriations

SEC. 104. (a) Section 5(a) of the Act is amended—

(1) by striking out "(a)" after "SEC. 5.";

(2) by inserting after the first sentence the following new sentence: "There are hereby further authorized to be appropriated for the purposes of this Act $33,500,000 for fiscal year 1984, $40,000,000 for fiscal year 1985, $41,500,000 for fiscal year 1986, and $43,100,000 for fiscal year 1987."; and

(3) in the second sentence by striking out "this section" and all that follows through the end of such subsection, and inserting in lieu thereof "this section except as provided in the succeeding sentence, (A) not

less than $9,000,000 shall be available in each fiscal year to carry out section 4(b) of this Act (relating to State grants), (B) not less than $11,000,000 shall be available in each fiscal year to carry out sections 4(a) (relating to demonstration or service projects), 2(b)(1) and 2(b)(3) (relating to information dissemination), 2(b)(5) (relating to research), and 4(c)(2) (relating to training, technical assistance, and information dissemination) of this Act, giving special consideration to continued funding of child abuse and neglect programs or projects (previously funded by the Department of Health and Human Services) of national or regional scope and demonstrated effectiveness, (C) $5,000,000 shall be available in each such year for grants and contracts under section 4(a) for identification, treatment, and prevention of sexual abuse, and (D) $5,000,000 shall be available in each such year for the purpose of making additional grants to the States to carry out the provisions of section 4(c)(1) of this Act. With respect to any fiscal year in which the total amount appropriated under this section is less than $30,000,000, funds shall first be available as provided in clauses (A) and (B) in the preceding sentence and of the remainder one-half shall be available as provided for in clause (C) and one-half as provided for in clause (D) in the preceding sentence.".

(b) Section 5(b) of the Act is repealed.

Advisory Board on Child Abuse and Neglect

SEC. 105. (a) The first sentence of section 6(a) of the Act is amended by striking out "including" and all that follows thereafter through "Administration,".

(b) Section 6(a) of the Act is further amended by inserting at the end thereof the following sentence: "The Advisory Board may be available, at the Secretary's re-

quest, to assist the Secretary in coordinating adoption-related activities of the Federal Government.".

(c)(1) Section 6(b) of the Act is repealed.

(2) Subsection (c) of section 6 of the Act is redesignated as subsection (b).

Coordination

SEC. 106. Section 7 of the Act is amended by striking out "between" and inserting in lieu thereof "among".

PART B—SERVICES AND TREATMENT FOR DISABLED INFANTS

New Definition

SEC. 121. Section 3 of the Act is further amended—

(1) by striking out "this Act the term 'child abuse and neglect'" and inserting in lieu thereof the following: "This Act—

"(1) the term 'child abuse and neglect'";

(2) by striking out the period at the end thereof and inserting in lieu thereof a semicolon and the word "and"; and

(3) by adding after clause (2) (as added by section 102(3) of this Act) the following new clause:

"(3) the term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in

the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survivial [sic] of the infant and the treatment itself under such circumstances would be inhumane.".

New Basic State Grant Requirement

SEC. 122. Section 4(b)(2) of the Act (42 U.S.C. 5103(b)(2)) is amended—

(1) by striking out "and" at the end of clause (I);

(2) by striking out the period at the end of clause (J) and inserting in lieu thereof a semicolon and the word "and"; and

(3) by inserting after clause (J) the following new clause:

"(K) within one year after the date of the enactment of the Child Abuse Amendments of 1984, have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of med-

ically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.".

Additional State Grants and Assistance for Training, Technical Assistance, and Clearinghouse Activities

SEC. 123. (a) Section 4 of the Act is further amended by—

(1) redesignating subsection (c) as subsection (d), subsection (d) as subsection (e), and subsection (e) as subsection (f); and

(2) inserting after subsection (b) the following new subsection:

"(c)(1) The Secretary is authorized to make additional grants to the States for the purpose of developing, establishing, and operating or implementing—

"(A) the procedures or programs required under clause (K) of subsection (b)(2) of this section;

"(B) information and education programs or training programs for the purpose of improving the provision of services to disabled infants with life-threatening conditions for (i) professional and paraprofessional personnel concerned with the welfare of disabled infants with life-threatening conditions, including personnel employed in child protective services programs and health-care facilities, and (ii) the parents of such infants; and

"(C) programs to help in obtaining or coordinating necessary services, including existing social and health

services and financial assistance for families with disabled infants with life-threatening conditions, and those services necessary to facilitate adoptive placement of such infants who have been relinquished for adoption.

"(2)(A) The Secretary shall provide, directly or through grants or contracts with public or private nonprofit organizations, for (i) training and technical assistance programs to assist States in developing, establishing, and operating or implementing programs and procedures meeting the requirements of clause (K) of subsection (b)(2) of this section; and (ii) the establishment and operation of national and regional information and resource clearinghouses for the purpose of providing the most current and complete information regarding medical treatment procedures and resources and community resources for the provision of services and treatment for disabled infants with life-threatening conditions (including compiling, maintaining, updating, and disseminating regional directories of community services and resources (including the names and phone numbers of State and local medical organizations) to assist parents, families, and physicians and seeking to coordinate the availability of appropriate regional education resources for health-care personnel).

"(B) Not more than $1,000,000 of the funds appropriated for any fiscal year under section 5 of this Act may be used to carry out this paragraph.

"(C) Not later than 210 days after the date of the enactment of the Child Abuse Amendments of 1984, the Secretary shall have the capability of providing and begin to provide the training and technical assistance described in subparagraph (A) of this paragraph.".

(b) Section 4 of the Act is further amended by adding after paragraph (3) the following new paragraph:

"(4) Programs or projects related to child abuse and neglect assisted under part B of title IV of the Social Se-

curity Act shall comply with the requirements set forth in clauses (B), (C), (E), (F), and (K) of paragraph (2).".

Regulations and Guidelines

SEC. 124. (a)(1) Not later than 60 days after the date of the enactment of this Act, the Secretary of Health and Human Services (hereinafter in this part referred to as the "Secretary") shall publish proposed regulations to implement the requirements of section 4(b)(2)(K) of the Act (as added by section 122(3) of this Act).

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a process of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish final regulations under this subsection.

(b)(1) Not later than 60 days after the date of the enactment of this Act, the Secretary shall publish interim model guidelines to encourage the establishment within health-care facilities of committees which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment (as that term is defined in clause (3) of section 3 of the Act (as added by section 121(3) of this Act)) from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions.

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a period of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish the model guidelines.

Report on Financial Resources

SEC. 125. The Secretary shall conduct a study to determine the most effective means of providing Federal finan-

cial support, other than the use of funds provided through the Social Security Act, for the provision of medical treatment, general care, and appropriate social services for disabled infants with life-threatening conditions. Not later than 270 days after the date of the enactment of this Act, the Secretary shall report the results of the study to the appropriate Committees of the Congress and shall include in the report such recommendations for legislation to provide such financial support as the Secretary considers appropriate.

Implementation Report

SEC. 126. Not later than October 1, 1987, the Secretary shall submit to the appropriate Committees of the Congress a detailed report on the implementation and the effects of the provisions of this part and the amendments made by it.

Statutory Construction

SEC. 127. (a) No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

(b) No provision of this Act or any amendment made by this Act may be so construed as to authorize the Secretary or any other governmental entity to establish standards prescribing specific medical treatments for specific conditions, except to the extent that such standards are authorized by other laws.

(c) If the provisions of any part of this Act or any amendment made by this Act or the application thereof to any person or circumstances be held invalid, the provisions of the other parts and their application to other persons or circumstances shall not be affected thereby.

Effective Dates

SEC. 128. (a) Except as provided in subsection (b), the provisions of this part or any amendment made by this part shall be effective on the date of the enactment of this Act.

(b)(1) Except as provided in paragraph (2), the amendments made by sections 122 and 123(b) of this Act shall become effective one year after the date of such enactment.

(2) In the event that, prior to such effective date, funds have not been appropriated pursuant to section 5 of the Act (as amended by section 104 of this Act) for the purpose of grants under section 4(c)(1) of the Act (as added by section 123(a) of this Act), any State which has not met any requirement of section 4(b)(2)(K) of the Act (as added by section 122(3) of this Act) may be granted a waiver of such requirements for a period of not more than one year, if the Secretary finds that such State is making a good-faith effort to comply with such requirements.

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In the Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

ON PETITION FOR WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

REPLY MEMORANDUM FOR THE PETITIONER

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The court of appeals has affirmed a sweeping nationwide injunction that permanently bars the Secretary from "any further implementation" of the regulations designed to protect handicapped newborn infants against the discriminatory withholding of medical care in federally assisted hospital programs and from "undertaking any other actions" pursuant to Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, with respect to the treatment of such infants. That decision is wrong and plainly warrants review by this Court. Respondents' attempts to minimize the effect of the decision below and to justify an implied exception from the broad terms of Section 504 for the denial of medical care even when based solely on the infant's handicap are without merit.

1. Respondents American Medical Association, et al. (AMA) make little effort to defend the broad holding of the court of appeals that Section 504 has no application whatever to a hospital's withholding of nourishment or treatment from a newborn infant solely because of his handicap. Nor does the AMA make

any serious effort to rebut our submission (Pet. 12-25) that the text, legislative history, and administrative interpretation of Section 504 firmly support application of that Section to such conduct. Respondents American Hospital Association, et al. (AHA) at least do address these issues, but to no avail.

a. The AHA does not dispute that the infants who are protected by the regulations invalidated by the court of appeals are "handicapped" within the meaning of Section 504. See Pet. 13-14. The AHA instead relies (Br. in Opp. 21-22, 24-25) on the language in Section 504 that prohibits discrimination against a handicapped individual only if he is "otherwise qualified." The AHA does not suggest that the infants protected by the regulations fail to meet any legitimate qualifications imposed by a program of federally assisted health care; indeed, it appears to concede that a person ordinarily need not possess any special qualifications to receive nourishment or beneficial treatment under such a program. But the AHA argues that because there are no special qualifications, an impaired newborn infant in need of treatment by a federally assisted hospital program cannot be regarded as "otherwise qualified" to receive that treatment. This argument makes no sense. It would have the perverse effect of exempting from the coverage of Section 504 *all* federally assisted programs and activities that are open to the public at large—the very ones in which there would be *no* programmatic justification for excluding handicapped persons from full participation. Compare *Southeastern Community College* v. *Davis*, 442 U.S. 397, 407 (1979).

b. Not surprisingly, the AHA offers no support in the legislative history for such a loophole. The AHA does argue (Br. in Opp. 22-23) that Section 504 is inapplicable in this setting because the Rehabilitation Act was designed to prohibit discrimination in vocational, employment, educational and similar programs, but not health services. This submission ignores the Senate Report on the 1974 Amendments, which specifically states that Section 504 applies to federal assistance in relation to "health services" (S. Rep. 93-1297, 93d Cong., 2d Sess. 38 (1974)). Moreover, in *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), this Court considered the effect of Section 504 on a State's furnishing of services under a state Medicaid program, without any intimation that Section 504 does not even apply to the furnishing of health services.

Although the AMA does not deny the application of Section 504 to health services to this extent, it does maintain (Br. in Opp. 20-24) that Section 504 should not apply to a hospital's "decision not to treat in an individual case" (Br. in Opp. 20). This argument flies in the face of the statutory language, which provides that "[n]o otherwise qualified *individual* * * * shall, solely by reason of *his* handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under" the federally assisted program or activity. 29 U.S.C. 794 (emphasis added). It would be of no solace to a handicapped individual who is denied treatment for his own particular condition to learn that the hospital does not have a broad policy of excluding handicapped persons generally.[1]

Finally, although the AHA objects (Br. in Opp. 26-27) to the parallel Judge Winter drew in his dissenting opinion below (Pet. App. 42a-45a) between a denial of medical treatment on the basis of race and such a denial on the basis of handicap (see also AMA Br. in Opp. 17 n.18), the AHA ignores the fact that this parallel is mandated by the text and legislative history of Section 504 itself, which unequivocally establish that it is patterned after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d *et seq.* See Pet. 19. It is true, as the AHA notes (Br. in Opp. 27), that this Court has

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[1]The AMA's related argument (Br. in Opp. 18-19) that Section 504 is concerned only with "access" to federal programs is refuted by the language and legislative history of the provision. As quoted in the text, Section 504 bars the recipient not only from excluding a handicapped person from the program altogether, but also from denying a handicapped person the benefits of the program or subjecting him to discrimination under it. The latter prohibitions clearly extend to a hospital's denial of medical treatment or protection to a handicapped person solely because of his handicap where that person already is a patient and thus was not entirely denied "access" to the hospital. The legislative history — including the only report cited by the AMA (see S. Rep. 92-1135, 92d Cong., 2d Sess. 49, 77 (1972)) — supports this reading as well. See S. Rep. 93-48, 93d Cong., 1st Sess. 53, 80 (1973); S. Rep. 93-318, 93d Cong., 1st Sess. 50, 70 (1973). See also S. Rep. 93-1297, 93d Cong., 2d Sess. 39 (1974) (emphasis added) (Section 504 establishes a "broad government policy" that federally assisted programs "shall be *operated* without discrimination on the basis of handicap").

observed that "too facile an assimilation of Title VI law to § 504 must be resisted" (*Alexander* v. *Choate*, slip op. 5 n.7). But that observation was made in connection with the question whether Section 504 reaches conduct that has the *effect* of discriminating on the basis of handicap. This case, by contrast, involves instances of *intentional* discrimination on the basis of handicap: the withholding of medical treatment from an impaired newborn infant "because of," not "in spite of," his handicap. Compare *Personnel Administrator* v. *Feeney*, 442 U.S. 256, 279 (1979). There is no reason to believe that Congress intended anything other than a direct parallel between handicap and race as regards such intentional discrimination.[2]

c. The AHA also repeats (Br. in Opp. 27-29) the court of appeals' erroneous assertion (Pet. App. 18a-25a) that HHS's interpretation of Section 504 is not entitled to deference because its position has not been consistent. As we have explained (Pet. 22-24), the regulations first promulgated by the Secretary in 1977 made clear that Section 504 applies to treatment decisions under federally assisted programs for the furnishing of health services (see 45 C.F.R. 84.55(a); *id.* Pt. 84, App. A para. 36), and the Secretary took the position in 1980—three years before the promulgation of the regulations at issue here—that Section 504 applies in the very context addressed by the regulations. Thus,

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[2]The AMA's objection (Br. in Opp. 19, 21-23) that the Secretary's interpretation creates a body of "[Section] 504 federal malpractice law" is without merit. The Secretary has not purported to fashion duties or rules of medical practice for physicians or hospitals generally. In her implementation of Section 504, the Secretary accepts the standards and reasonable medical judgments of the profession, and insists only that handicapped persons be afforded "evenhanded treatment" (*Alexander* v. *Choate*, slip op. 16) in their application. Contrary to the AMA's suggestion that the Secretary "may not even have the advice of medical consultants" (Br. in Opp. 20), the guidelines that accompany the Section 504 regulations specifically state that "[t]he Department will obtain the assistance of a qualified medical consultant to evaluate the medical information (including medical records) obtained in the course of a preliminary inquiry or investigation" (Pet. App. 71a).

the AHA is flatly wrong in stating that HHS first took this position "beginning in 1982" (Br. in Opp. 28).[3]

2. The AMA seeks to avoid the application of Section 504 by focusing on other matters: the role of parents and the state-law origins of a hospital's duties. Neither of these factors excuses a hospital from complying with Section 504.

a. The AMA first points out (Br. in Opp. 15, 20-21) that parents are responsible in the first instance for making decisions regarding the treatment of their infant children. The AMA then states that the Secretary makes what it terms the "devastating concession" (*id.* at 16) that parental decisionmaking is outside the scope of Section 504 because parents are not recipients of federal financial assistance within the meaning of Section 504. From these premises, the AMA concludes that the Secretary cannot do indirectly (by enforcing Section 504 against hospitals) what she cannot do directly (regulate parental decisionmaking). There are numerous flaws in this reasoning.

That Section 504 does not reach parental decisionmaking is not a "devastating concession"; it is a self-evident proposition. But we fail to see what that has to do with the issues in this case. The Secretary has not attempted to impose duties on parents under Section 504. But hospitals, unlike parents, *are* the recipients of federal financial assistance for their programs and activities, and they accordingly *do* have a duty of nondiscrimination under Section 504.

Moreover, although the AMA discusses the issues presented primarily in the context of situations in which the parents withhold their consent to appropriate treatment, the regulations and

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[3]Contrary to the further misleading contention by the AMA and AHA (AMA Br. in Opp. 22 n.22; AHA Br. in Opp. 28), the Secretary in 1976 rejected only the view that Section 504 confers on institutionalized persons an *absolute* right to treatment. As we have explained (Pet. 23-24), the Secretary's decision on that issue did not address the distinct question of the application of Section 504 to discrimination in the *relative* treatment of handicapped and nonhandicapped persons. See Pet. 23-24.

interpretative guidelines also apply where parents give their consent but the hospital refuses to treat the infant solely because of his handicap. See 45 C.F.R. Pt. 84, App. C paras. (a)(1) and (4); Pet. App. 66a-67a. In the latter situation, the parents' role obviously cannot immunize the hospital's conduct from scrutiny under Section 504. The AMA does not argue otherwise. Yet the nationwide injunction affirmed by the court of appeals in this case permanently bars the Secretary from investigating or taking enforcement action in that setting (Pet. App. 51a-52a).

In any event, contrary to the AMA's contention, Section 504 is not rendered inapplicable (and a hospital is not relieved of all responsibilities under Section 504) in those instances in which the parents have withheld their consent to medically indicated treatment. This Court has recognized that the "state is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized." *Parham* v. *J.R.*, 442 U.S. 584, 603 (1979). See also *Prince* v. *Massachusetts*, 321 U.S. 158 (1944); *Santosky* v. *Kramer*, 455 U.S. 745 (1982). The AMA likewise does not appear to question that a hospital may seek to override parental decisions when it determines that those decisions are not in the child's best interests. It is this independent responsibility of the *hospital* that is addressed by Section 504. Section 504 does not impose a new duty on a hospital; it simply requires that a hospital act in a nondiscriminatory manner in exercising its *existing* authority under state law to take appropriate steps in instances of medical neglect by parents, taking the same steps for a handicapped child as it would for a nonhandicapped child.

Nor, finally, does the enforcement of Section 504 in this manner result in the Secretary's accomplishing indirectly something she is barred from doing directly. Section 504 does not affirmatively prohibit the Secretary from taking steps that affect parental decisionmaking; it simply does not reach or address parents' decisions as such because parents are not recipients of federal financial assistance. Further, it is state law, not Section 504, that regulates and in appropriate circumstances overrides the parents' decisions. The hospital discharges its obligation under Section 504 by invoking state processes to protect a handicapped

child in the same manner as it would a nonhandicapped child. From that point, it is the state processes, not Section 504, that may affect parental decisionmaking.

b. The AMA also argues (Br. in Opp. 18-19) that the nondiscrimination obligation under Section 504 does not attach to a hospital's performance of its duty to take measures where parents refuse to consent, on the ground that the latter duty arises under state law. This argument wholly ignores the historical purpose of federal civil rights laws generally to ensure that powers conferred by state law are not exercised so as to discriminate on a ground that is prohibited by federal law. See U.S. Const. Amend. XIV (No State shall "deny to any person within its jurisdiction the equal protection of the laws."). The AMA's argument (Br. in Opp. 18-19) that this responsibility under state law is not part of the federally assisted "program or activity" therefore must fail. The obligation or authority of a hospital to take steps to protect a child who is medically neglected by his parents attaches because the hospital has taken the child into its care for treatment under the federally assisted program or activity, and the invocation of state processes is intended to override parental decisions that operate against the child's interests and thereby to facilitate the fulfillment of the objectives of the program or activity insofar as it affects the child. The hospital's actions thus are an integral part of its federally assisted functions. Indeed, there presumably are many aspects of the operations of most recipients of federal funds that are independently regulated by state law, but this has never been thought to exempt those aspects from the coverage of federal antidiscrimination statutes.

3. Finally, both the AMA and AHA argue (AMA Br. in Opp. 24-26; AHA Br. in Opp. 13-17) that Congress's passage of a provision in the comprehensive Child Abuse Amendments of 1984 that addresses the furnishing of medical care to seriously ill infants (Pub. L. No. 98-457, § 122, 98 Stat. 1752) casts doubt on the validity of the Secretary's regulations under Section 504 and suggests that the Court should deny review in this case. These arguments are without merit.

The relevant provision of the 1984 Amendments requires a state child protective services agency, as a condition to the receipt of federal funds under the Child Abuse Prevention and Treatment Act (42 U.S.C. 5101 *et seq.*), to establish procedures and programs for responding to the reporting of instances of withholding of medically indicated treatment from disabled infants who have life-threatening conditions. See Pet. 26-27 n.22. Those Amendments do not address the distinct duty under federal law of a federally assisted *hospital* to take steps to assure that a handicapped child in its care is not denied needed medical treatment solely because of his handicap. Indeed, Section 127(a) of the 1984 Amendments (98 Stat. 1754) expressly states that "[n]o provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973."

Moreover, contrary to the impression sought to be conveyed by the AMA and AHA, the legislative history of the 1984 Amendments does not cast doubt on the Secretary's interpretation of Section 504 or suggest that the protection afforded by Section 504 now is unnecessary. The requirement that a state child protective services agency adopt procedures to respond to instances of the withholding of medical treatment originated in the House bill. See H.R. Rep. 98-159, 98th Cong., 1st Sess. 2, 19 (1983). The report on that bill endorsed the application of Section 504 in this setting. It explained that the state agency's actions were necessary to assure that the child would receive specified treatment, "including services assured under the provisions of section 504 of the Rehabilitation Act of 1973" (H.R. Rep. 98-159, *supra*, at 3), and the bill itself provided that it was not to be construed to "lessen" or "limit" any right or protection under Section 504 (H.R. Rep. 98-159, *supra*, at 27). Similarly, the floor debates on the House bill contain numerous statements that the denial of medical care to handicapped infants in such cases is a form of discrimination, that the bill would reaffirm the civil rights of handicapped children that already were protected by Section 504, and that the bill would build upon and complement

the Secretary's efforts under Section 504.[4] There was, by contrast, no statement by any Member that the Section 504 regulations were beyond the Secretary's authority or would be rendered superfluous if the bill was enacted.

The Senate Report contains a detailed discussion of evidence of the withholding of medical care from severely ill newborn infants. S. Rep. 98-246, 98th Cong., 1st Sess. 5-11 (1983). It observes that the practice "may be more widespread" than indicated by a leading study; cites surveys indicating that a majority of pediatricians would honor a parent's wishes not to treat a newborn child with Down's Syndrome who had an intestinal blockage and would not recommend surgery to the parent; and estimates that 400 infants with spina bifida may be subjected to some form of non-treatment during each year (*id.* at 8-9). The report concludes that if this information is correct, "then federal policy on the civil rights of handicapped persons[] is being contravened." *Id.* at 9. See also *id.* at 11.

The Senate ultimately adopted the language that was enacted by Congress, with minor revisions in conference. The Senators who sponsored the compromise language indicated that they adopted in it a "policy of neutrality" regarding the application of Section 504 and that this intent was reflected in the language of Section 127(a) providing that nothing in the 1984 Act "is intended to affect any right or protection under Section 504" (130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984)). Congress's action therefore does not suggest that Section 504 is inapplicable in this setting or that this Court should decline to resolve that important question.

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[4] 130 Cong. Rec. H379 H380, (daily ed. Feb. 2, 1984) (remarks of Rep. Murphy); *id.* at H381, H382, H384, H385 (remarks of Rep. Erlenborn); *id.* at H388 (remarks of Rep. Biaggi); *id.* at H393 (remarks of Rep. Chandler); *id.* at H395 (remarks of Rep. Hyde); *id.* at H396, H400 (remarks of Rep. Miller); *id.* at H397 (remarks of Rep. Quillen). See also *id.* at H396 (remarks of Rep. Waxman) (supporting proposal, subsequently defeated, to amend House bill; noting that amendment would not affect Section 504 regulations, which must stand or fall on their merits).

From the beginning, the 1984 Amendments were viewed by Congress as a complement to, not a substitute for, whatever protections were afforded to such infants by Section 504. Congress had no occasion to address the distinct duty of a hospital under that Section in legislation that imposed new obligations on child protection agencies. The court of appeals, however, has permanently enjoined the Secretary, on a nationwide basis, from taking any steps under Section 504 to enforce this distinct duty. Especially in view of the importance Congress attached to protection for impaired newborn infants in 1984, the court of appeals' broad ruling warrants review by this Court. The court of appeals' judgment essentially extinguishes any right or protection such infants have under Section 504. Respondents' argument that the Court should deny review of that judgment because of Congress's enactment of the 1984 Amendments is inconsistent with Congress's express statement in Section 127(a) that those Amendments should *not* "affect any right or protection" under Section 504.

For the foregoing reasons and the additional reasons stated in the petition, it is respectfully submitted that the petition for a writ of certiorari should be granted.

CHARLES FRIED
Acting Solicitor General

JUNE 1985

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No. 84-1529

IN THE
Supreme Court of the United States
OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Petition for a Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF FOR AMICUS CURIAE AMERICAN ACADEMY OF PEDIATRICS IN OPPOSITION TO A PETITION FOR WRIT OF CERTIORARI

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BRIEF FOR AMICUS CURIAE AMERICAN ACADEMY OF PEDIATRICS IN OPPOSITION TO A PETITION FOR WRIT OF CERTIORARI

The American Academy of Pediatrics (the "Academy") submits this brief *amicus curiae* in support of Respondents American Hospital Association, *et al.*, in opposition to the Petition for a Writ of Certiorari filed by Secretary Margaret M. Heckler ("the Secretary") of the Department of Health and Human Services ("HHS"). It is accompanied by the written consents of Petitioner and Respondents.

INTEREST OF AMICUS CURIAE

The Academy is a non-profit organization comprised of more than 28,000 board-certified pediatricians, the majority of whom practice medicine in hospitals which would

be affected by any decision of this Court concerning the application of Section 504 of the Rehabilitation Act of 1973 ("Section 504"), 29 U.S.C. § 794, to medical treatment of seriously ill infants. Through professional policy papers and in educational programs of all kinds, the Academy serves as an advocate of children and their right to medical care. Through grants awarded by the Department of Education, Office of Special Education and Rehabilitative Services, the Academy has developed state by state education programs for pediatricians to work with school systems in furnishing education for handicapped children throughout the country. In addition, the Academy's Committee on Bioethics has coordinated educational programs concerning the bioethical dimensions of pediatric treatment decisions involving handicapped children, and has developed statements of bioethical principles for Academy adoption.

The Academy has also been actively involved in judicial and administrative proceedings considering the applicability of Section 504 to medical treatment decisions. First, the Academy was the lead plaintiff in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983), *appeal dismissed*, No. 83-1407 (D.C. Cir. Aug. 4, 1983), which invalidated an "interim final rule" (48 Fed. Reg. 9630 (March 7, 1983)) promulgated under Section 504 concerning discrimination against handicapped infants. Second, the Academy presented detailed comments to HHS in response to proposed rules (48 Fed. Reg. 30846 (July 5, 1983)) regarding discrimination on the basis of handicap in medical treatment of newborns. These rules, in revised form, are the regulations at issue in this case. 49 Fed. Reg. 1622 (Jan. 12, 1984).[1]

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[1] The Academy also played a central role in promoting a consensus among members of Congress and representatives of various medical, right-to-life and disability groups on the legislation which was ultimately enacted as the Child Abuse Amendments of 1984, Pub. L. 98-457, 98 Stat. 1749 *et seq.* Petitioner has recognized that support by medical associations, such as the Academy, was "essen-

Since the instant case deals squarely with the issue of whether Section 504 provides a basis for the federal government to investigate and intervene in individual medical treatment decisions concerning impaired newborns, the Academy believes it is important to reiterate its concerns on this issue for the benefit of this Court.

ARGUMENT

Review on writ of certiorari is not a matter of right and should only be granted when there are "special and important reasons therefor." Sup. Ct. R. 17.1. Because the United States Court of Appeals for the Second Circuit, after an exhaustive review of the statute and legislative history of Section 504 in *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984),[2] correctly held that Section 504 does not authorize federal intervention into medical treatment decisions in the manner contemplated by Petitioner's rules, there is no reason for this Court to consider this issue.

Moreover, partially in reaction to the decisions in *University Hospital* and *American Academy of Pediatrics*, Congress enacted the Child Abuse Amendments of 1984

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tial to accomplishing [this] legislative compromise. . . ." 50 Fed. Reg. 14879 (April 15, 1985). Subsequently, the Academy presented extensive comments to HHS in response to proposed rules implementing the amendments (49 Fed. Reg. 48160 (Dec. 10, 1984)). Comments of the American Academy of Pediatrics on Proposed Rule Regarding Child Abuse and Neglect Prevention and Treatment Program and Interim Model Guidelines for Infant Care Review Committees (49 Fed. Reg. 48160, 48170 (Dec. 10, 1984)) (Feb. 8, 1985). In part due to consideration of the Academy's comments, these rules were substantially revised when published in final form. 50 Fed. Reg. 14878 (April 15, 1985).

[2] In the decision below, American Hospital Association v. Heckler, Nos. 84-6211, 84-6213 (2d Cir. Dec. 27, 1984) (*per curiam*), *aff'g by unpublished order*, 585 F. Supp. 541 (S.D.N.Y. 1984), the Court of Appeals summarily affirmed the district court's judgment on the basis of *University Hospital*.

Pub. L. 98-457, 98 Stat. 1749 *et seq.*, thus resolving the issue of federal-state responsibility for investigating reports of inappropriate withholding of medical treatment and obviating the need for review of this case. Petitioner's suggestion (Petition for Writ of Certiorari ("Pet.") at 12) that, in the absence of review by this Court, medical treatment decisions concerning disabled infants will be "cloaked with blanket immunity" from scrutiny and will result in maltreatment of infants is thus totally unfounded and fundamentally misrepresents the state of the law as it applies to disabled infants. Accordingly, the Petition for a Writ of Certiorari should be denied.

I. THE COURT OF APPEALS CORRECTLY HELD THAT SECTION 504 OF THE REHABILITATION ACT DOES NOT AUTHORIZE FEDERAL INTERVENTION INTO MEDICAL TREATMENT DECISIONS REGARDING SERIOUSLY IMPAIRED NEWBORNS

The expansive reading of Section 504 urged by Petitioner is unsupported by the statute's legislative history and is contrary to established judicial precedent concerning the scope of the discrimination prohibition in Section 504. The statute simply does not authorize federal intervention in the critical care nursery in the manner contemplated by Petitioner's rules.

A. Congress Did Not Intend That Section 504 Serve As the Basis for Federal Intervention In Medical Decisionmaking

This Court has recognized that "language as broad as that of § 504 cannot be read in isolation from its history and purposes." *Consolidated Rail Corp. v. Darrone*, 104 S. Ct. 1248, 1254 n.13 (1984). To determine the scope of Section 504, it is necessary to examine congressional intent. Contrary to Petitioner's suggestion (Pet. at 18), the legislative history of Section 504 is not "sparse" as to Congress' intent. In fact, the legislative history clearly indicates that Congress was initially only concerned with

discrimination against handicapped individuals in terms of employment. *See, e.g.*, 119 Cong. Rec. 24,587 (1973) (remarks of Sen. Taft on S. 1875, 93d Cong., 1st Sess. (1973)).[3] Later, this goal was expanded to remove barriers to access in education, transportation, and social services.[4] Yet contrary to Petitioner's assertion (Pet. at 18), the expansion of the scope of the statute in no way indicates that Congress intended Section 504 to authorize federal regulation of medical treatment decisions. To the extent that Congress even contemplated "health services" as being subject to Section 504, it did so only in the sense of requiring providers to make such services equally available to all persons who are able to meet a particular program's requirements in spite of their handicap, a far different situation than the intrusion into individual medical care decisions contemplated by Petitioner's rule. *See* S. Rep. No. 1297, 93d Cong., 2d Sess. 38, *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6388-89. The only specific reference to medicine or health services in the legislative history is in the context of access to nursing home services:

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[3] Accordingly, Congress originally defined the phrase "handicapped individual" in terms of employment:

> The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services. . . .

Section 7(6), Pub. L. No. 93-112, 87 Stat. 355.

[4] As part of the Rehabilitation Act Amendments of 1974 (Pub. L. 93-516, § 111(a), 88 Stat. 1619), Congress expanded the definition to encompass "impairments to major life activities." Under the 1974 amendments, a "handicapped individual" is:

> any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

> Examples of handicapped individuals who may suffer discrimination in the receipt of Federally-assisted services but who may have been unintentionally excluded from the protection of Section 504 by the references to enhanced employability in section 7(6) are as follows:
>
> * * * *
>
> admission to Federally-assisted nursing homes on the basis of their handicap. . . .

Id.

Petitioner asserts that by patterning Section 504 after Title VI of the Civil Rights Act, 42 U.S.C. §§ 2000d *et seq.*, Congress intended that Section 504's prohibition against discrimination because of handicap be construed as broadly as the prohibition of racial discrimination in Title VI. Pet. at 19. Yet the very decisions of this Court cited by Petitioner demonstrate that Section 504 does not constitute the sweeping prohibition of discrimination on the basis of handicap that Title VI mandates for discrimination on the basis of race. In *Alexander v. Choate*, 105 S. Ct. 712, 717 (1985), this Court wrote that "there are reasons to pause before too quickly extending [case law interpreting Title VI] to § 504." Similarly, in *Consolidated Rail*, 104 S. Ct. at 1254 n.13, this Court noted that there are significant distinctions between the purposes and scope of Title VI and Section 504. Indeed, this Court's decisions have recognized that Section 504 does not mandate a total ban on distinctions in federally-funded programs between individuals on the basis of handicap. *See Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *cf. Community Television of Southern California v. Gottfried*, 459 U.S. 498 (1983) (holding that Section 504 does not require the Federal Communications Commission to alter its standard for reviewing public television license renewal applications to include consideration of the needs of the hearing-impaired).

Moreover, Petitioner proposes an overly simplistic analogy between Title VI and Section 504. Petitioner argues

(Pet. at 19) that just as a federally assisted hospital cannot, under Title VI, refuse to perform surgery to remove an intestinal obstruction in an infant solely because of his race, so too the hospital cannot, under Section 504, refuse to perform the surgery because of the infant's "handicap" (*e.g.*, Down's Syndrome). This argument ignores the fact that whereas race is never a proper consideration in a decision to provide medical services, the type of "handicap" to which Petitioner refers is integrally related to, and often an essential consideration in, a decision as to what type of medical treatment is appropriate. *See University Hospital*, 729 F.2d at 156. In fact, Petitioner concedes (Pet. at 20 n.17) that it "may be more difficult [to apply Section 504] in such circumstances because of the interrelatedness of the medical considerations." *See* 49 Fed. Reg. 1637 (1984).[5]

In sum, no part of the legislative history of the Rehabilitation Act of 1973 indicates a congressional concern with individual medical decisions, much less physician and parental decisions concerning complex medical treatment for critically ill newborns and infants. In addressing the scope of Section 504 in the context of disparate-impact discrimination, this Court expressly noted that had Congress intended the statute to reach all such claims, "we would expect some indication of that purpose in the statute or its legislative history. Yet there is nothing to suggest that such was Congress' purpose." *Alexander v. Choate*, 105 S. Ct. at 720. The same is true in this case. Had Congress intended Section 504

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[5] Petitioner nevertheless contends that the existence of difficult cases does not justify the wholesale exclusion of medical treatment decisions from Section 504. Pet. at 20 n.17. As will be shown in detail below, because the Child Abuse Amendments of 1984 and the regulations promulgated thereunder ensure that seriously ill infants will not be deprived of medically indicated treatment, the absence of Section 504 enforcement poses no danger to such infants. If anything, the presence of the intrusive federal measures for which Petitioner claims authority could endanger the health of these infants. *See infra* pp. 13-20.

to reach medical treatment decisions, some indication of this intent would be evident in the legislative history. As noted by the United States Court of Appeals for the Second Circuit, "the failure of congress [sic] to focus on treatment decisions involving defective newborn infants strikes a telling blow to the government's position." *University Hospital*, 729 F.2d at 160.[6]

B. Petitioner's Section 504 Analysis Violates Judicial Decisions Concerning the Scope of the Application of Section 504

Case law interpreting Section 504 uniformly establishes that the statute has a limited scope. First, the statute only prohibits discrimination against "otherwise qualified" handicapped individuals. Second, Section 504 cannot be interpreted to impose unwarranted affirmative action burdens on providers. Petitioner's expansive reading of Section 504 ignores both of these limitations.

1. *A Seriously Impaired Newborn Infant Is Not An "Otherwise Qualified" Handicapped Individual*

This Court in *Southeastern Community College v. Davis* held that an otherwise qualified individual is "one who is able to meet all of a program's requirements in spite of his handicap." 442 U.S. at 406. *See also Doe v. New York University*, 666 F.2d 761, 775 (2d Cir. 1981). The legislative and earlier regulatory history of Section 504 make clear that a health care provider may not discriminate against a handicapped individual when the individual's handicap is unrelated to the provision of medical services. In the same way that a hospital is prohibited from refusing to treat individuals because of their

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[6] In American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983), *appeal dismissed*, No. 83-1407 (D.C. Cir. Aug. 4, 1983), Judge Gesell also noted that while Section 504 was open to broad interpretation, "no congressional committee or member of the House or Senate *ever even suggested* that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life." *Id.* at 401 (emphasis added).

race under Title VI of the Civil Rights Act of 1964 (Pet. 17 n.13), a hospital is prohibited by Section 504 as a general policy from refusing to treat handicapped individuals solely because of their handicap, because that does not involve an individual treatment decision and because the handicap typically is entirely unrelated to the medical treatment at issue.

The Secretary, however, improperly argues that when a "handicap" is related to the infant's need for treatment, a hospital is prohibited by Section 504 from basing a treatment decision in a particular case in any part on the "handicap." Pet. at 15 and n.11. The analogy to Title VI breaks down when applied to medical decisionmaking because the medical handicap is typically inextricably intertwined with the treatment decision itself. *See University Hospital*, 729 F.2d at 156.[7]

For example, in *University Hospital*, the child involved, "Baby Jane Doe," suffered from multiple birth defects, including: myelomeningocele (commonly known as spina bifida); microcephaly, an abnormally small head; hydrocephalus, accumulated fluid in the cranial vault; a "weak face," which prevented her from closing her eyes or making a full suck with her tongue; a malformed brain stem; upper extremity spasticity; and a thumb implanted in her fist. 729 F.2d at 146.[8] Obviously, treatment of any

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[7] As discussed at p. 6, this Court has cautioned against being too quick to draw analogies between Title VI and Section 504. Alexander v. Choate, 105 S. Ct. at 717; *Consolidated Rail*, 104 S. Ct. at 1254 n.13.

[8] The diversity and complexity of Baby Jane Doe's medical impairments is not unique; most infants with medical problems suffer from varied and complex medical impairments. Infants suffering from prematurity and immaturity, particularly with extreme hypoxic stress at birth, and complications of intensive care, such as chronic lung disease and compromised intestinal function, constitute a large population, conservatively estimated at 30,000 live births annually. *See* Comments of the American Academy of Pediatrics on Proposed Rule Regarding Child Abuse and Neglect Prevention and Treatment Program and Interim Model Guidelines for

of these impairments would have to be based on the infant's entire medical profile. Petitioner concedes as much by admitting that the application of Section 504 is somewhat tortured in the context of medical treatment decisions "because of the interrelatedness of the medical considerations." (Pet. at 20 n.17.) Since medical treatment necessarily depends on the specific illness or injuries present, *any* decision by a hospital not to treat one particular condition could be said to have been made "solely on the basis of the infant's handicap," and thus, in the view of Petitioner, in violation of Section 504. Congress cannot be assumed to have intended such an absurd result. Moreover, Petitioner's analysis has no support in the language, legislative history or case law interpreting Section 504, and this reasoning was specifically rejected by the Second Circuit. *University Hospital*, 729 F.2d at 156-57.

A further bar to applying Section 504 to medical treatment decisions concerning disabled infants is that an infant's medical condition is constantly changing—what the *University Hospital* court termed the "fluid context of medical treatment decisions." 729 F.2d at 156. In programs or activities that are fixed or "static" in nature, such as education, employment and transportation, certain standards on handicapped availability or access to a particular program can be established, as can appropriate modifications to accommodate the handicapped. Medical treatment decisions, on the other hand, depend on the changing conditions of the patient. As Judge Gesell emphasized in *American Academy of Pediatrics v. Heckler*, "*there is no customary standard of care* for the treatment of severely defective infants." 561 F. Supp. at 400 (emphasis in original). Thus, an inquiry into "discrimination" in this context is meaningless when different treatment decisions are appropriate depending on the

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Infant Care Review Committees (49 Fed. Reg. 48160, 48170 (Dec. 10, 1984)) (Feb. 8, 1985).

particular infant and his or her changing medical conditions.

2. *Petitioner's Final Rule Would Improperly Require Affirmative Action by Hospitals*

This Court also recognized in *Southeastern Community College v. Davis* that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." 442 U.S. at 411. In *Davis*, a licensed practical nurse contended that her denial of admission to a college nursing program on the basis of her hearing disability violated Section 504. As part of her argument, she asserted that regulations implementing Section 504 required that the nursing program be modified to accommodate her, to which this Court replied:

> If these regulations were to require substantial adjustments in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals, they would do more than clarify the meaning of § 504. Instead, they would constitute an unauthorized extension of the obligations imposed by that statute.

Id. at 410. This Court thus distinguished the provision of equal opportunity from affirmative action, stating that "[t]he language and structure of the Rehabilitation Act of 1973 reflect a recognition by Congress of the *distinction between the evenhanded treatment* of qualified handicapped persons *and affirmative efforts to overcome the disabilities* caused by handicaps." *Id.* (emphasis added). This Court found that Section 504 does not impose any requirements upon institutions to take substantive steps outside their ordinary programs to eliminate or overcome handicaps. *Id.* at 413.

Similarly, in *Doe v. New York University*, 666 F.2d 761, the Second Circuit rejected the claim of a mentally handicapped student who sought readmission to medical school. The court found that the school was "not obligated by the Act to alter, dilute or bend [its admission standards] to admit the handicapped applicant." 666

F.2d at 775. Petitioner's rules—potentially requiring hospitals to undertake surgery notwithstanding parental consent, or resort to state courts to override parental consent—clearly require hospitals to undertake extensive affirmative action. The rules would not only obligate the provider to "alter" or "bend" its procedures for making medical treatment decisions, but require the provider to undertake legal actions outside of its internal decision-making structure. Such a total transformation of the provider's process of rendering health care clearly exceeds the type of modifications that are permissible under Section 504.

This Court has also recognized that interpretation of Section 504 must keep the statute "within manageable bounds." *Alexander v. Choate*, 105 S. Ct. at 720-21 n.20. Section 504 cannot serve as a basis for a "burdensome . . . mandate" on federally assisted activities or programs. *American Public Transit Association v. Lewis*, 655 F.2d 1272, 1278 (D.C. Cir. 1981). Petitioner's rules constitute exactly the kind of burdensome and disruptive measures that are beyond the requirements authorized by these judicial decisions. Under Petitioner's rules, nonmedical teams of HHS employees, designated by HHS as "Baby Doe Squads," would be granted expedited access to investigate any report of suspected discriminatory treatment of impaired infants. 45 C.F.R. § 84.55(e). As noted by Judge Gesell, the intrusion of these "Baby Doe Squads" into hospitals would impose unwarranted burdens on hospitals, and would endanger the health of the infant:

> [A]ny anonymous tipster, for whatever personal motive, can trigger an investigation involving immediate inspection of hospital records and facilities and interviewing of involved families and medical personnel. In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of "Baby Doe" squads on the scene, monopolizing physician and nurse time and making

> hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

American Academy of Pediatrics v. Heckler, 561 F. Supp. at 399 (footnote omitted). Certainly, Congress did not intend Section 504 to authorize intervention which would harm the very individuals it is purporting to protect from discrimination.

II. THE CHILD ABUSE AMENDMENTS OF 1984 AND THE REGULATIONS PROMULGATED THEREUNDER OBVIATE THE NEED FOR REVIEW

On October 9, 1984, Congress adopted amendments to the Child Abuse and Treatment Act (42 U.S.C. §§ 5101 *et seq.*), Pub. L. 98-457, 98 Stat. 1749 *et seq.* [hereinafter the "Amendments"]. In contrast to Section 504, the Amendments employ a grant program to build on existing state mechanisms for dealing with child abuse and neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.

To receive grants for its child protective services ("CPS") system, a state must establish procedures for: (1) consultation with designated individuals in hospitals; (2) notification of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions); and (3) legal remedies, under state law, for the CPS agency to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions. Section 122, 98 Stat. 1752-53 (amending 42 U.S.C. § 5103(b)(2)(K)). The federal role is limited to establishing a clearinghouse for information regarding developments in treatment and support services for disabled infants, and to promulgating regulations to ensure that states fulfill their obligations under the statute.[9] As noted by Senator Hatch, a principal sponsor of the

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[9] Sections 123(a), 124(a), 98 Stat. 1753-54.

1984 Amendments, the "legislation does not itself authorize direct federal involvement in individual cases." 130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984) (letter from Sen. Hatch to Sen. Weicker).

On December 10, 1984, the Secretary published a Notice of Proposed Rulemaking (49 Fed. Reg. 48160) and, following a comment period, on April 15, 1985, issued final regulations (50 Fed. Reg. 14878) implementing the 1984 Amendments. Consistent with the Amendments and their legislative history, these regulations rely on state implementation and enforcement procedures to deal with reports of suspected or known medical neglect: "We believe it is the clear intent of Congress that States utilize their existing child protective services system to carry out this new responsibility [under the Amendments]." 50 Fed. Reg. 14883; *see id.* at 14882-84, 14887-88.[10] Petitioner admits that the procedures established by the Child Abuse Amendments are similar to those which it earlier required under Section 504, the authority for which is at issue here. Pet. at 26-27 n.22.

A. The Child Abuse Amendments Represent Congress' Belief that Medical Treatment Decisions Regarding Seriously Impaired Newborns Are Best Dealt With Under Existing State Mechanisms

Passage of the Child Abuse Amendments must be viewed in the context of the developments preceding what Petitioner has conceded was an "extraordinary effort" to

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[10] Pursuant to section 124(b) of the Amendments, 98 Stat. 1754, the Secretary also issued Model Guidelines for Health Care Providers to Establish Infant Care Review Committees to encourage the creation of infant care review committees (ICRCs) in hospitals. 50 Fed. Reg. 14893 (April 15, 1985). The Academy strongly supports the establishment of ICRCs to provide consultation and to ensure that sensitive treatment decisions are made in a reasoned, informed, and caring manner. Such committees, in conjunction with the procedures established through the state child protective services system, ensure that when treatment is medically indicated, the infant will receive appropriate care.

enact legislation in this most sensitive area. 50 Fed. Reg. at 14879. Following the highly-publicized "Baby Doe" case in Bloomington, Indiana, in the spring of 1983, HHS promulgated an "interim final rule," without prior notice or opportunity for public comment, requiring hospitals receiving federal financial assistance to post notices stating: "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law." The rule also provided that anyone having knowledge that a handicapped infant was being discriminatorily denied food or customary medical care should contact a 24-hour-a-day "Handicapped Infant Hotline." Through the hotline *anyone*—a passerby, a disgruntled employee—could report what they considered to be suspicious hospital behavior. *See* 48 Fed. Reg. 9630 (Mar. 7, 1983).

Soon after the interim rule was proposed, the Academy and two other plaintiffs filed suit challenging the rule. In *American Academy of Pediatrics v. Heckler*, Judge Gesell struck down the rule, finding that HHS lacked a rational factual basis for the rule and that the agency had failed to follow required notice and comment procedures. 561 F. Supp. at 403. Judge Gesell cited numerous shortcomings in the rule, including the disruptive effect of HHS' enforcement procedures in caring for disabled newborns. *Id.* at 399. He also suggested that this issue "be clarified by further congressional action." *Id.* at 402.

HHS then issued a new proposed rule and solicited public comment. 48 Fed. Reg. 30846 (July 5, 1983) (proposed rule modifying 45 C.F.R. § 84.61). While HHS was in the process of preparing its final rule, the case of the infant "Baby Jane Doe" again raised the question of HHS' authority under Section 504 to intervene in medical treatment decisions, which led, after extensive proceedings, to the *University Hospital* decision.

Thus, in the fall of 1984 when Congress adopted the Child Abuse Amendments, it was well aware of the seri-

ous questions raised by these cases regarding the legal authority—let alone the wisdom—of federal intervention in medical treatment decisions. *See, e.g.*, S. Rep. No. 246, 98th Cong., 2d Sess. 6-8 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2918, 2922-25; 130 Cong. Rec. S8952 (daily ed. June 29, 1984) (remarks of Sen. Nickles). The Senate Report noted that "[t]he highly publicized recent cases have catapulted the issue of withholding treatment from seriously ill infants into the public arena . . . ." S. Rep. No. 246, 98th Cong., 2d Sess. 6 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2923.[11] Since the same subcommittees in the Senate Labor and Human Resources Committee and the House Education and Labor Committee have jurisdiction over both Section 504 and the child abuse and neglect grant program, Congress could easily have overruled *University Hospital* by expressly including coverage of medical treatment decisions of disabled infants in Section 504. Instead, Congress chose to assist the states in carrying out their traditional role in the area of child abuse and neglect.[12]

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[11] Congressional recognition of judicial interpretation of Section 504 is supported by the fundamental principle of statutory construction that:

> Congress does not legislate in a vacuum; Congressional legislation must be viewed in light of earlier legislation enacted in connection with the same subject matter and court decisions which have definitely determined the meaning and scope of that earlier legislation.

Application of United States, 407 F.Supp. 398, 405 (W.D. Mo. 1976).

[12] In the 1984 legislative session, Congress did consider amending Section 504, primarily to overrule this Court's decision in Grove City College v. Bell, 104 S. Ct. 1211 (1984). *See* H.R. 5490, 98th Cong., 2d Sess. (1984); S. 2568, 98th Cong., 2d Sess. (1984). Yet nothing in the proposed amendments indicates that Congress believed Section 504 applies, or should apply, to medical treatment decisions regarding disabled infants. None of the sponsors of the legislation, in presenting it to the full Senate, even mentioned disabled infants. For example, Senator Cranston, a co-sponsor of the amendments and principal author of Section 504, stressed that

As recognized by this Court, the "failure of Congress to alter [a statute] after it had been judicially construed, and the enactment by Congress of legislation which implicitly recognizes the judicial construction as effective, is persuasive of legislative recognition that the judicial construction be the correct one." *Apex Hosiery Co. v. Leader*, 310 U.S. 469, 488 (1940); *see also Blue Chip Stamps v. Manor Drug Stores*, 421 U.S. 723, 732-33 (1975); *Lewis v. United States*, 663 F.2d 889, 891 (9th Cir. 1981), *cert. denied*, 457 U.S. 1133 (1982). Moreover, the subsequent interpretation of the federal role in medical treatment decisions concerning disabled infants by the same congressional committees that originally enacted Section 504 is "virtually conclusive" as to Congress' prior intended meaning. *Sioux Tribe of Indians v. United States*, 316 U.S. 317, 329 (1942); *see also Socony Mobil Oil Co. v. United States*, 287 F.2d 910, 914 (Ct. Cl. 1961); *accord Abell v. United States*, 518 F.2d 1369 (Ct. Cl. 1975), *cert. denied*, 429 U.S. 817 (1976). Given Congress' clear decision to let the *University Hospital* decision stand and adopt state-based enforcement procedures instead, there is no reason for this Court to review the decision below.[13]

B. The Child Abuse Amendments Maintain A Careful Balance Between Protecting the Rights of Disabled Infants and the Need to Avoid Unreasonable Governmental Intervention, Thus Rendering Review by This Court Unnecessary

Unlike Section 504, in which there was no discussion of medical treatment decisions, the Child Abuse Amend-

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the statute was intended to prevent discrimination in employment and education. 130 Cong. Rec. S4595 (daily ed. April 12, 1984) (remarks of Sen. Cranston).

[13] While it is true that the Child Abuse Amendments provide that nothing in the statute "is intended to affect any right or protection under Section 504 of the Rehabilitation Act of 1973," Section 127(a), 98 Stat. 1754, it is also true that in addressing the issue of medical care of disabled infants, Congress chose to use the state CPS system rather than authorizing federal intervention under Section 504.

ments were the product of extensive congressional negotiations which ultimately resulted in a legislative compromise. The Secretary has repeatedly recognized (50 Fed. Reg. 14881) that "the essence of this compromise" was based on the "careful balance" between the need to protect the rights of disabled infants and the need to avoid intrusive and inflammatory governmental intervention in medical decisionmaking:

> It is clear that the legislation represent[s] a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities.

Id. at 14879 (April 15, 1985). The Secretary also stated that the success of implementing the program to monitor and report medical neglect depended on the need to maintain the broad consensus that had sponsored this important legislation: "It was and continues to be of great importance to the Department to preserve and advance this consensus in order to most effectively implement this program." *Id.* at 14879.

Congress deemed it appropriate to utilize the existing state CPS system instead of Section 504 for several reasons. First, all states have a CPS agency, whether they receive state grant funds or not. These child abuse agencies have recognized expertise in the area of child abuse and neglect. *See* 50 Fed. Reg. 14878 (April 15, 1985). Second, many state agencies have already developed relationships with individuals in hospitals to report cases of suspected child abuse and neglect. *See* 49 Fed. Reg. 1631 (Jan. 12, 1984). Third, the framers agreed that procedural requirements should be based on existing state administrative and enforcement mechanisms, rather than creating a new system or bureaucracy of "medical neglect." The Secretary has acknowledged congressional concern over the administrative problems of creating "a new system and a new bureaucracy" to respond to the health care needs of disabled infants. 50 Fed. Reg. 14881.

The Child Abuse Amendments thus represent Congress' determination after extensive debate that the appropriate means to respond to the needs of disabled infants is through the state CPS, not Section 504. Inquiry by this Court into the Secretary's authority under Section 504 is therefore unnecessary.

Petitioner contends that, absent her rules, disabled infants will receive no protection. Pet. at 26. Yet by Petitioner's own admission, the Child Abuse Amendments and regulations promulgated thereunder, ensure the "meaningful protection of the rights of disabled infants to receive appropriate medical care[.]" 50 Fed. Reg. 14881. If anything, disabled infants receive *greater* protection from state CPS agencies since such agencies, unlike HHS's "Baby Doe Squads," have the requisite experience, expertise, professional contacts with hospitals, and enforcement mechanisms to protect the best interests of the child. Petitioner's implementation of a prior, similar rule was disastrous: "Baby Doe Squads" descended on hospitals, disrupting complex medical care and diverting the attention of physicians and nurses caring for the infants. In at least one case, a family withdrew a seriously ill patient from a hospital before completion of treatment because they believed that somehow the hospital that was being investigated was intentionally harming their child.[14] As observed by Judge Gesell, the sudden descent of "Baby Doe Squads" interrupting medical care "can hardly be presumed to produce higher quality care for the infant." *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 399. The Amendments, on the other hand, guarantee that severely disabled infants will receive appropriate medical care while

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[14] *See, e.g.*, Affidavit of Norman B. Urmy (submitted as an attachment to the Memorandum of Law filed by the National Association of Children's Hospitals and Related Institutions (NACHRI)), and Affidavit of Paul M. Rosenberg (submitted as an attachment to the Amicus Brief filed by the American Hospital Association, Respondent in this case) in American Academy of Pediatrics v. Heckler, 561 F. Supp. 395.

avoiding unwarranted intrusion of the federal government in medical and parental decisionmaking. Thus, contrary to Petitioner's suggestion (Pet. 26-27 n.22), the Amendments effectively dispose of the need to review this case.

CONCLUSION

For the reasons set forth herein, the Petition for a Writ of Certiorari should be denied.

Respectfully submitted,

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May 24, 1985

Supreme Court, U.S.
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AUG 31 1985
JOSEPH F. SPANIOL, JR.
CLERK

No. 84-1529

In the Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

JOINT APPENDIX

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CERTIORARI GRANTED JUNE 17, 1985

BEST AVAILABLE COPY

In the Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

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JOINT APPENDIX

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IN THE UNITED STATES DISTRICT COURT FOR THE SOUTHERN DISTRICT OF NEW YORK

Civil Action No. 83 Civ. 2638 (CLB)
AMERICAN HOSPITAL ASSOCIATION,
ON BEHALF OF ITS MEMBER HOSPITALS,
HOSPITAL ASSOCIATION OF NEW YORK STATE,
ON BEHALF OF ITS MEMBER HOSPITALS,
STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER, PLAINTIFFS

v.

MARGARET M. HECKLER, SECRETARY, UNITED STATES
DEPARTMENT OF HEALTH AND HUMAN SERVICES

RELEVANT DOCKET ENTRIES

DATE	NR.	PROCEEDINGS
04-06-83	1	Fld complaint & issued summons & notice purs to 28:636(c)
4-6-83	2	Fld. ORDER TO SHOW CAUSE FOR P.I. AND TRO ... ordered that pending the hearing of pl: application to a P.I. the defts. are temporarily restrained and enjoined from enfor. 45 CFR 84.61(a)(b) solely to the extent it purports to require the posting of notice upon the premises of voluntary or municipal hospitals within N.Y.S. etc. further that security to be posted by the pltffs is not necessary ... BRIEANT, J. Issued 4-6-83 Ret. 4-18-83.
4-15-83	4	Fld. pltffs. memo in support of motion for P.I. and TRO.
4-15-83	—	Fld. Memo-Endorsed on doc. #2 ... motion granted. Settle a proposed injunction order on 3 days notice. See Transcript of hearings this date and previously. BRIEANT, J.

4-28-83	5	Fld. ORDER that this action is transferred to the Suspense Docket of this Court, pending resolution of litigation presently pending in the Court of Appeals for the District of Columbia or pending further order of this Court. BRIEANT, J. mn
5-4-83	6	Fld. PRELIMINARY INJUNCTION ... Ordered that sufficient reason having been shown there for the defts are enjoined and restrained from enforcing 45 CFR 84.61 within N.Y.S. during the pendency of this action or until further order of this Court. Bond is unnecessary. BRIEANT, J. mn
3-12-84	10	FLd. pltffs. notice of motion & affdvt for an order of preliminary injunction. Ret. 3-23-84
3-12-84	11	Fld. pltffs. memo of points and authorities in support of motion.
3-12-84	12	Fld. AMENDED COMPLT.
3-22-84	13	Fld. defts opposition to pltffs motion for preliminary injunction.
3-23-84	14	Fld. pltffs reply to defts opposition to motion for preliminary injunction.
3-23-84	15	Fld. ORDER that the action is transferred from the Suspense Docket to active docket and this action and 84 civ 1724 CLB are consolidated for purposes. All papers hereafter filed shall be docketed under 83 civ BRIEANT, J. mn
5-18-84	18	Fld. pltffs supplemental memo on effect of Grove City College V. Bell.
5-18-84	19	Fld. pltffs supplemental memorandum.
5-23-84	20	Fld. MEMO & ORDER...Settle final declaratory judgment on 5 days notice. BRIEANT, J. mn
6-11-84	23	Fld. FINAL JUDGMENT...Ordered that the Final regulation and all actions implement it are declared invalid and unlawful as exceeding the scope of defts authority under section 504 of the Rehabilitation Act

		of 1973, 29 USC 794, etc. Defts are permanently enjoined from any further implementation of the Final Regulation with respect to any program or activity receiving Federal financial assistance...etc. BRIEANT, J, JUDGMENT ENTERED 6-11-84...CLERK (EOD on 6-12-84.)
6-11-84	24	Fld. defts Ex parte motion for order extending the time to submit counterproposed judgment.
6-11-84	—	Fld. Memo-Endorsed on doc. #24...This is a totally useless motion which should be and is denied, etc. BRIEANT, J.
7-9-84	28	Fld. defts NOTICE OF APPEAL to the USCA-Second Circuit from the judgment entered on 6-11-84. Mailed notice to Benjamin W. Heineman, Jr at 1722 Eye St. N.W. Washington D.C. 20006, Newton N. Minow at One First National Plaza, Chicago, Illinois 60603, Steven M. Bierman at 520 Madison Avenue, NYC 10022, Stuart M. Gerson at 1140 19th Street N.W. Suite 9000, Washington D.C. 20036 and Lawrence Washburn, Jr at 521 5th Ave. NYC 10175 on 7-11-84.
7-11-84	—	COPY OF NOTICE OF APPEAL FORWARDED TO DISTRICT JUDGE AND COPY OF NOTICE OF APPEAL AND DOCKET ENTRIES TO C.A.
7-11-84	29	Fld. pltffs notice of motion for an order staying until no later than 30 days after appellate disposition of this case the submission by AHA of documentary material in support of its application for an award of attys fees, etc. Ret. 7-23-84
7-11-84	30	Fld. pltffs memo in support of motion for an order staying submission, etc.
7-11-84	31	Fld. pltffs application for award of attys fees and costs.

7-17-84	35	Filed Order...Ordered that the submission by AHA of documentary or other material in support of its application for an award of attys' fees is stayed until no later than 30 days after final appellate disposition of this case...BRIEANT.

IN THE UNITED STATES DISTRICT COURT FOR
THE SOUTHERN DISTRICT OF NEW YORK

Civil Action No. 84 Civ. 1724 (CLB)

AMERICAN MEDICAL ASSOCIATION,
AMERICAN HOSPITAL ASSOCIATION,
HOSPITAL ASSOCIATION OF NEW YORK STATE,
AMERICAN COLLEGE OF OBSTETRICIANS
AND GYNECOLOGISTS,
ASSOCIATION OF AMERICAN MEDICAL COLLEGES,
AMERICAN ACADEMY OF FAMILY PHYSICIANS,
HUBERT A. RITTER, M.D.,
PETER A.M. AULD, M.D.,
RITA GILMAN HARPER, M.D.,
ROY HOWARD PETRIE, M.D.,
PLAINTIFFS

v.

MARGARET M. HECKLER, SECRETARY, DEPARTMENT
OF HEALTH AND HUMAN SERVICES

RELEVANT DOCKET ENTRIES

DATE	NR.	PROCEEDINGS
3-12-84	1	Filed Complaint-Issued Summons & Notice purs. to 28 USC 636(c).
3-12-84	3	Filed Pltffs' Notice of Motion for an Order granting preliminary injunction. Motion returnable on 03-23-84.
3-12-84	4	Filed Memorandum of Points & Authorities in Support of Pltffs' Motion for Preliminary Injunction.
3-12-84	4	Filed Appendices in Support of Pltffs' Motion for Preliminary Injunction.
3-12-84	6	Filed Pltffs' Notice of Motion Consolidating the instant case with American Hospital Association vs Heckler. Motion returnable on 03-23-84.

3-12-84	7	Filed Memorandum of Points & Authorities in Support of Pltffs' Motion for Consolidation.
3-14-84	8	FLD. NOTICE OF ASSIGNMENT TO JUDGE BRIEANT. Mn.
3-15-84	9	Fld. pltffs. SDNY General Rules Rule 9 Certification.
3-22-84	11	Fld. defts memo of points and authorities in opposition to motion for preliminary injunction.
3-23-84	12	Fld. pltffs reply memo of points and authorities in support of motion for a preliminary injunction.
3-23-84	—	Fld. ORDER that this action is consolidated with 83 civ 2638 CLB for all purposes and all papers shall be filed and docketed under 83 civ BRIEANT, J. mn
6-11-84	13	Fld. FINAL JUDGMENT...Ordered that defts are permanently enjoined from any further implementation of the Final Regulation with respect to any program or activity receiving Federal financial assistance. See 29 USC 794 and 29 USC 706(14), etc. BRIEANT, J. JUDGMENT ENTERED 6-11-84. CLERK. (EOD on 6-12-84)
7-9-84	15	Fld. defts NOTICE OF APPEAL to the USCA-Second Circuit from the judgment entered on 6-11-84. Mailed notice to Benjamin W. Heineman, Jr at 1722 Eye ST. NW. Washington D.C. 20006, Newton N. Minow at 1 First National Plaza, Chicago, Illinois 60603, Steven M. Bierman at 520 Madison Avenue, NYC 10022, Stuart M. Gerson at 1140 19th St. NW Washington DC 20036 and Lawrence Washburn, Jr at 521 Fifth Ave. NYC 10175 on 7-11-84
7-11-84	—	COPY OF NOTICE OF APPEAL FORWARDED TO DISTRICT JUDGE AND

		COPY OF NOTICE OF APPEAL AND DOCKET ENTRIES TO C.A.
7-11-84	16	Fld. pltffs notice of motion for an order of attys fees, etc. Ret. 7-23-84
7-11-84	17	Fld. pltffs memo of points and authorities in support of motion.
12-11-84	18	Fld. pltffs application for award of attys fees and costs.

IN THE UNITED STATES COURT OF APPEALS
FOR THE SECOND CIRCUIT

Docket No. 84-6211

AMERICAN HOSPITAL ASSOCIATION,
ON BEHALF OF ITS MEMBER HOSPITALS,
HOSPITAL ASSOCIATION OF NEW YORK STATE,
ON BEHALF OF ITS MEMBER HOSPITALS,
STRONG MEMORIAL HOSPITAL OF
THE UNIVERSITY OF ROCHESTER,
PLAINTIFFS-APPELLEES

v.

MARGARET M. HECKLER, SECRETARY, UNITED STATES
DEPARTMENT OF HEALTH & HUMAN SERVICES

Docket No. 84-6213

AMERICAN MEDICAL ASSOCIATION,
AMERICAN HOSPITAL ASSOCIATION,
HOSPITAL ASSOCIATION OF NEW YORK STATE,
AMERICAN COLLEGE OF OBSTETRICIANS
AND GYNECOLOGISTS,
ASSOCIATION OF AMERICAN MEDICAL COLLEGES,
AMERICAN ACADEMY OF FAMILY PHYSICIANS,
HUBERT A. RITTER, M.D.
PETER A.M. AULD, M.D.
RITA GILMAN HARPER, M.D.
ROY HOWARD PETRIE, M.D.,
PLAINTIFFS-APPELLEES

v.

MARGARET M. HECKLER, SECRETARY, DEPARTMENT OF
HEALTH AND HUMAN SERVICES

RELEVANT DOCKET ENTRIES

DATE	FILINGS—PROCEEDINGS
7-12-84	Copy of district court docket entries and notice of appeal on behalf of appellant Heckler filed (& in 84-6213)

8-3-84	Appellant motion for an original hearing in banc filed. (w/pfs)
8-10-84	Appellees affidavit in opposition to appellant motion for an original hearing in banc filed. (w/pfs)
8-10-84	Appellees AMA response in opposition to appellants' motion for an original hearing in banc filed. (w/pfs)
8-22-84	Order denied appellant motion for an original hearing in banc filed.
9-20-84	Record on appeal filed. (original papers of the district court proceedings)
9-26-84	Appellant motion for summary disposition without briefing or oral argument filed. (w/pfs)
10-2-84	Appellant brief filed w/ps (by mail)
10-9-84	Appellees AMA opposition to defendant appellants motion for summary disposition without briefing or oral argument w/pfs filed.
10-09-84	Appellees AHA response to defendant appellants motion for summary disposition without briefing or oral argument w/pfs filed.
10-25-84	Appellee AHA briefs filed (w/pfs) (page proofs)
10-25-84	Appellee AMA briefs filed (w/pfs) (page proofs)
11-2-84	Appellant HECKLER motion for extension of time for filing reply brief filed pfs.
11-7-84	Order granted appellant motion to extend time to file reply brief filed (Endorsed on motion filed 11-2-84)
11-7-84	Appellees American Medical Assoc. et al. brief filed w/ps (& in 84-6213)
11-8-84	Appellees American Hospital Assoc. et al. brief filed w/ps (& in 84-6213)
11-8-84	Deferred Joint-appendix filed w/ps (& in 84-6213)
11-16-84	Appellant Margaret Heckler reply brief filed (w/pfs)
12-27-84	Judgment Affirmed, detailed court order without opinion filed (& in 84-6213) (JON, GCP, JWP)
1-18-85	Mandate Issued (judgment)
4-8-85	Notice of filing of petition for writ of certiorari filed on behalf of M. Heckler (S.C. #84-1529)

6-19-85	Certified copy of order by Supreme Court granting petition for writ of certiorari filed

[49 Fed. Reg. 1622 (Jan. 12, 1984)]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

45 CFR Part 84

Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants

AGENCY: Office of the Secretary, HHS.

ACTION: Final rules.

SUMMARY: These are final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants. These rules are issued under the authority of section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap in programs and activities receiving Federal financial assistance.

EFFECTIVE DATE: February 13, 1984.

FOR FURTHER INFORMATION CONTACT: Susan Shaloub, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, SW., Room 5514, Washington, D.C. 20201; telephone (202) 245-6585. TDD No. (202) 472-2916.

SUPPLEMENTARY INFORMATION:

I. Synopsis

These rules are the product of a careful analysis of nearly 17,000 comments submitted to the Department during the comment period provided by the proposed rules of July 5, 1983. On the basis of this analysis, the Department has made significant modifications to the proposed rules. These modifications are designed to establish a framework under which the substantial controversy that has attended the Department's efforts to strengthen enforcement of section 504 in this area can be replaced by a more cooperative effort involving the Federal Government, the medical community, private advocacy groups and state governments.

These final rules continue the Department's efforts to put in place an effective mechanism for enforcing section 504 in connection with health care for handicapped infants.

But they also initiate new efforts to make unnecessary the use of those Federal enforcement mechanisms by encouraging hospitals to establish policies and procedures to implement the principle that treatment decisions for handicapped infants be based on reasonable medical judgments, and medically beneficial treatment not be withheld solely on the basis of an infant's present or anticipated mental or physical impairments.

In seeking to forge a cooperative approach, the Department is encouraged by the recent development of "Principles of Treatment of Disabled Infants" by the following major medical and disability organizations: American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association of America, American Coalition of Citizens with Disabilities, the Association for the Severely Handicapped, American Association on Mental Deficiency, and American Association of University Affiliated Programs for the Developmentally Disabled. Announced November 29, 1983, in Washington, D.C., these principles state:

> When medical care is clearly beneficial, it should always be provided.* * * Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.
>
> It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.
>
> In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be

> the basis for a decision to withhold treatment. * * * When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

In the issuance of these final rules, the Department seeks to build upon the spirit of cooperation underlying this landmark statement of principles. The major elements of the final rules are as follows:

First, the Department adopts the recommendation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research that the Federal government encourage hospitals to establish review procedures concerning life and death decisions affecting seriously ill newborns. The rules include a model Infant Care Review Committee to assist hospitals in this effort.

Second, the rules require the posting in hospitals of an informational notice regarding the legal rights of handicapped infants. The notice requirements have been revised to permit hospitals to highlight their own policies and internal review procedures, in addition to the federal law and government contact points.

Third, the rules require that state child protective services agencies have established procedures for applying their own state laws protecting children from medical neglect.

Fourth, the appendix to the rules sets forth interpretative guidelines for applying the law in these cases. These guidelines restate the Department's interpretation that section 504 requires that health care providers not withhold nourishment or medically beneficial treatment from a handicapped infant solely on the basis of present or anticipated physical or mental impairments, but it does not interfere with reasonable medical judgments, nor require the provision of futile treatments.

Fifth, the appendix to the rules sets forth guidelines for HHS investigations of alleged civil rights violations relating to health care for handicapped infants. These guidelines provide for the participation of hospital Infant Care Review Committees, the avoidance of unnecessary investigations, the involvement of qualified medical consultants, and the protection of confidential information.

The Department hopes the issuance of these rules, which become effective in 30 days, will end the controversy that has surrounded their development. But more importantly, it is hoped the rules will foster a new process of cooperative efforts and sensible approaches to advance the principle that life and death medical treatment decisions be based on informed judgments of medical benefits and risks, and not on stereotypes and prejudices against handicapped persons.

II. Background

On April 30, 1982, President Reagan instructed the Secretary of Health and Human Services:

> to notify health care providers of the applicability of section 504 of the Rehabilitation Act of 1973 to the treatment of handicapped patients. That law forbids recipients of federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps. Regulations under this law specifically prohibit hospitals and other providers of health services receiving federal assistance from discriminating against the handicapped.
>
> * * * * *
>
> Our nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced.

The President's instructions followed reports of the death, in Bloomington, Indiana, of an infant with Down's syndrome, from whom available surgical treatment to repair a detached esophagus was withheld.

On May 18, 1982, HHS issued to approximately 7,000 hospitals a notice stating:

> Under section 504 it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; (2) the handicap does not render

the treatment or nutritional sustenance medically contraindicated.

Soon after this notice, the HHS Office for Civil Rights (OCR) established expedited investigative procedures to deal with any case of a suspected discriminatory withholding of lifesustaining nourishment or medical treatment from a handicapped inf[illegible].

On March 7, 1983, HHS issued, with a scheduled effective date of March 22, 1983, an interim final rule requiring recipient hospitals to post "in a conspicuous place" in pertinent wards a notice advising of the applicability of section 504 and the availability of a telephone "hotline" to report suspected violations of the law.

On April 14, 1983, the Honorable Gerhard Gesell, United States District Judge for the District of Columbia, declared the interim final rule invalid on the grounds that it was "arbitrary and capricious" and that there was inadequate justification for waiving a public comment period prior to issuance of the regulation. *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Judge Gesell declined to order the Department to discontinue use of the hotline.

On July 5, 1983, HHS issued a proposed rule in which the notice requirement was revised; provisions were added concerning state child protective service agencies; an appendix of standards and examples was added; and a 60-day comment period was provided. 48 FR 30846.

The Department received 16,739 comments, of which 16,331 (97.5%) supported the proposed rule, and 408 (2.5%) opposed it. Other aggregate descriptions are:

—Of 322 nurses, 314 (97.5%) supported, and 8 (2.5%) opposed it.

—Of 141 pediatricians or newborn care specialists, 39 (27.7%) favored, and 102 (72.3%) opposed it.

—Of 253 physicians, not including pediatricians or newborn care specialists, 140 (55.3%) favored, and 113 (44.7%) opposed it.

—Of 137 comments from hospital officials and medical, hospital, nursing and other health related association, 31 (22.6%) supported and 106 (77.4%) opposed it.

—Of 77 comments from associations representing the handicapped, all supported the proposed rule.

—Of 100 parents of handicapped persons, 95 (95%) supported and 5(5%) opposed it.

In addition to the written comments received, a number of meetings were held after issuance of the proposed rule with representatives of interested groups. The principal HHS officials involved in these meetings were the Under Secretary and the Surgeon General. Minutes of these meetings were kept and have been included in the public comment file.

Every comment was read and analyzed. Readers determined whether the commenter was in favor of, or opposed to, the proposed rule and identified particular points made by the commenter. The decisions made by the Department in connection with the rule are based not on the volume of comments advancing any point, but on thorough consideration of the merits of the comments submitted.

III. Provisions of the Final Rules

A. INFANT CARE REVIEW COMMITTEES

The March 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research included the following recommendation:

> The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants.... Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone....
>
> Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.

In response to a question included in the preamble, the Department received many comments regading hospital review boards. Many commenters who expressed opposition to the rule, particularly health care providers, expressed a strong preference for the hospital review board approach over the proposed rule or any implementation or enforcement of section 504. Others opposed hospital review boards, particularly as an alternative to the proposed rule and existing HHS procedures.

The American Academy of Pediatrics, which submitted the most detailed proposal, suggested, as an alternative to the proposed rule, that all hospitals, as a condition of participation in the Medicare program (not as a requirement of section 504), establish a review committee. Under this proposal (also endorsed by the National Association of Children's Hospitals and Related Institutions, and in concept, the American Hospital Association) the committee would have three functions: (1) To develop hospital policies and guidelines for management of specific types of diagnoses; (2) to monitor adherence through retrospective record review; and (3) to review, on an emergency basis, specific cases when the withholding of life-sustaining treatment is being considered. When the committee disagreed with a parental or physician decision to withhold treatment, the case would be referred to the appropriate court or child protective agency, and treatment would be continued pending a decision. Committee membership would include a hospital administrator, a representative of a disability group, a lay community member, a member of the hospital's medical staff, and a practicing nurse.

Among the arguments advanced in favor of the creation of hospital review boards, as a substitute for the approach set forth in the proposed rule, were:

(a) They would represent a cooperative approach between the government and the health care community, rather than a confrontational approach.

(b) They would provide a vehicle by which facility "self-evaluations" can be conducted.

(c) They would assure an indepth review by persons of varied perspectives of individual, complex cases involving critically ill infants.

(d) They would provide a mechanism for ensuring that hospitals, physicans and parents are informed of the most recent medical information concerning treatment of handicapped infants and of community services, counselling, parent support groups, and such alternative care options as adoption, foster care, and other out-of-home placements.

(e) They would lead to the involvement of child protective agencies and of the courts where it is indicated that the interests of the child are not being served.

Many commenters who expressed support for the proposed rule also expressed strong opposition to the alternative approach of hospital review boards because:

(a) Such boards cannot replace State and federal government responsibilities to protect the rights of citizens. The use of review boards would not assure that all individuals with disabilities would receive nondiscriminatory treatment as guaranteed by section 504.

(b) Such boards are virtually untested as a viable mechanism to protect handicapped infants from discriminatory practices.

A number of commenters, including the American Medical Association, the Catholic Health Association, the Federation of American Hospitals, the American College of Hospital Administrators, the American College of Physicians, the American Nurses Association, and other medical groups, expressed support for the concept of review boards, but opposed any mandate that review boards be established. The AMA added:

> While we do not support federal intervention in treatment decisions concerning seriously ill newborns, the attention brought about by the government's action should provide a continued stimulus to develop mechanisms to deal with these sensitive matters without the intrusion of the federal government into an area where it does not belong.

Response

The Department believes there is much merit in many of the comments submitted both in favor of, and in opposition to, utilization of hospital review boards to assist in the devel-

opment of standard policies and protocols and to review individual cases. The Department's conclusions are as follows.

First, the Department believes review committees cannot be given an exclusive role in reviewing medical decisions concerning the withholding or withdrawal of medical or surgical treatments from handicapped infants, and thus, cannot accept the proposal of hospital review boards as a *substitute* for mechanisms to enforce section 504.

The Department does not seek to take over medical decisionmaking regarding health care for handicapped infants. HHS agrees that the best decisionmakers are generally the parents and the physicians directly involved. However, there is, and must be, a framework within which the decisionmakers, the parents and physicians, operate.

That framework is established by laws. With respect to health care professionals providing services under programs or activities receiving federal financial assistance, the framework includes section 504, which prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. With respect to parents, the laws are state laws establishing limitations on parental authority. With respect to both the federal law and the respective state laws, each specifically provides implementation mechanisms involving government agencies.

The fundamental issue involved in deciding whether review boards should be a substitute for enforcement of section 504 is whether the legal framework within which the decisionmaking parents and physicians are supposed to function (and generally do function) will be utilized.

Under the proposal that review boards act in lieu of government, whether physicians or hospital review boards adhere to the principles of section 504 would be determined by those physicians and boards alone. Whether parents, physicians, or review boards adhere to state laws on the limitations of parental authority would be decided by the same physicians and boards. Whether they ever utilize the implementation schemes established by law to ensure that those principles are adhered to would also be decided by those parents, physicians, and review boards.

The Department concludes that the essential element of this alternative proposal—that it separates the process from the established legal framework governing decisionmaking by parents and physicians, with no meaningful provision to ensure that they function in accord with this framework—makes the proposal unacceptable as a substitute for the proposed rule. This alternative proposal simply does not provide sufficient safeguards that the requirements of section 504 will be met. Because section 504 is applicable to the provision of health care services to handicapped infants in programs and activities receiving Federal financial assistance, the Department believes it would not be justifiable for the Department to refrain from exercising a regulatory role to enforce the statute.

Second, the Department concludes that, although unacceptable as a substitute, review boards can be very valuable. The Department agrees with the rationale of the President's Commission and many commenters that input from a committee that includes individuals with medical expertise and people with non-medical perspectives and that is guided by proper standards and protocols can be very helpful in bringing about informed, enlightened and fair decisionmaking regarding these difficult issues. The Department, therefore, adopts the recommendation of the President's Commission that the government encourage establishment of hospital review boards.

Third, the Department concludes that the creation of hospital review boards should not be mandated by the Federal government. The Department agrees with the President's Commission that because review boards are "largely untried", they are not so demonstrably effective as to justify making them mandatory for nearly 7,000 hospitals nationwide. Also, there would be very substantial practical problems in seeking to enforce such a mandate with respect to so many hospitals. To make such a mandate viable, it would have to be accompanied by detailed standards on how to organize and operate the committee. The Department agrees with the President's Commission that flexibility is needed for each hospital to consider the best approach for itself. For example, the review board procedures may be

unnecessary for small or rural hospitals that rarely encounter cases involving severely impaired newborns and that handle such cases by immediately transferring the infant to the appropriate specialty hospital.

In addition, in view of the strong opposition by major medical organizations to mandatory committees, there would likely be protracted legal proceedings challenging the regulation, whether adopted pursuant to section 504 or pursuant to authority under the Social Security Act to establish conditions of participation and standards for the Medicare and Medicaid programs.

For these reasons, the Department has concluded that Infant Care Review Committees should be encouraged, but not mandated by the federal government.

Fourth, the Department concludes that the establishment of review boards will be facilitated by the development of a model committee. Therefore, § 84.55(f) of the rules sets forth a model Infant Care Review Committee (ICRC). This model calls for broad representation and significant involvement of the ICRC in developing standard policies and protocols for the hospital and in promptly reviewing specific cases. The model is based substantially on comments submitted by the American Academy of Pediatrics.

The Department has revised the Academy's model somewhat to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504, the recommendations of the President's Commission and the landmark "Principles of Treatment of Disabled Infants." The Department has also revised the Academy's model to provide, in connection with review of specific cases, for the designation of one member of the ICRC as "special advocate" for the infant. While recognizing that all members of the ICRC should be advocates for the best interests of the infant, the role of the special advocate will be to ensure that all considerations in favor of the provisions of life-sustaining treatment are fully evaluated and considered. As the President's Commission stated, "it is all too easy to undervalue the lives of handicapped infants." The special advocate feature of the model ICRC provides a mechanism to counteract this tendency.

This model is also consistent with the recommendations of the President's Commission and the comments of the American Hospital Association and other medical organizations. The Department also acknowledges the comment of the American Medical Association that the government's actions provide "a continued stimulus" for the medical community "to develop mechanisms to deal with these sensitive matters." HHS strongly encourages medical organizations to follow through on their suggestions and provide all possible assistance to their member institutions and medical professionals in establishing and operating these ICRC's.

B. INFORMATIONAL NOTICE

The proposed rules required that recipient hospitals post "in a conspicuous place in each nurse's station" of appropriate wards a notice stating:

> DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW
>
> * * * * *
>
> Any person having knowledge that a handicapped infant is being discriminatory denied food or customary medical care should immediately contact:
> Handicapped Infant Hotline
>
> * * * * *
>
> Failure to feed and care for infants may also violate the criminal and civil laws of your state.

A number of commenters expressed a concern that the posting of the required notice would itself have a disruptive effect on the provision of health care to newborn infants by creating the impression to an infant's parents, already in a very stressful situation, that the physician, nursing staff, and hospital should not be trusted to provide proper care to their child. In connection with this point, the Catholic Health Association suggested that hospitals be permitted to use an alternative notice allowing the hospital to state its agreement with the policy of nondiscrimination and indicate the appropriate hospital contact person. Another comment suggested alternatives to posting, such as placing the notice

on the admitting document or on consent forms used by the hospital.

Some commenters considered the wording of the notice very ambiguous in its references to "discriminatory failure" and "customary medical care" and in its failure to make reference to futile treatments, deference to legitimate medical judgments, the nonapplicability of section 504 to parental decisions, and many distinctions and nuances relating to the applicability of section 504 in this context.

Other criticisms were that the words "should immediately contact" improperly implied a legal obligation to report; the reference to "this facility" implied prior misconduct by that facility; and the reference to violations of "the criminal and civil laws of your state" is inappropriate because it does not relate to the purpose of the notice to inform people about civil rights protections.

A number of commenters suggested additions to the notice, including: a reference to the sanctions for noncompliance; express inclusion of handicapped infants born alive after abortions; reference to physical, mental, or emotional abuse or injury or withholding of fluids, oxygen, medications, warmth, and routine nursing care; and a statement that callers are not required to identify themselves.

Other commenters urged that hospitals be required to notify HHS that the notice has been posted.

Response

In an effort to accommodate many of these concerns, the Department has made a number of changes regarding the wording of the informational notice and the locations where it is to be posted. However, the Department remains convinced of the need for a notice to advise individuals in a position to know about potentially discriminatory conduct of the requirements of the law and of the mechanisms available to report suspected violations expenditiously so that, should a violation be occurring, corrective action can be taken in time to save the infant's life.

In many other contexts of civil rights enforcement and enforcement of scores of other statutes, speed is not essential because the victim of discrimination can be essentially "made

whole" through reinstatement in a job, admission to a school or hospital, retroactive benefit payments, or the like. However, in the context of life and death medical decisons, the matter must be handled with the utmost urgency. For this reason, the Department continues to believe that it is essential to meaningful implementation of the requirements of section 504 to have a mechanism for immediate reports of suspected violations.

However, the Department has concluded that it can, without detracting from this overriding objective, eliminate the unintended adverse effects of the notice many commenters perceived. Therefore, the informational notice requirements set forth in § 84.55(b) reflect significant modifications from those set forth in the proposed rules.

First, the Department has adopted the suggestion of the Catholic Health Association that hospitals be permitted to post a notice reflecting that the hospital's policy is consistent with the nondiscrimination requirements of section 504 and that the hospital also has a mechanism to review suspected noncompliance with this policy. This change eliminates any perception that the notice implies improper conduct by the hospital.

The only requirement contained in the rule for the use of this notice (identified in the regulation as "Notice A") is that the content of the notice be truthful as it relates to that hospital. To be truthful, the hospital must have a policy that nourishment and medically benefical treatment, as determined with respect for reasonable medical judgments, should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments. Furthermore, the hospital must have a procedure for review of treatment deliberations and decisions concerning health care for handicapped infants. Also, so that potential callers will be assured that the hospital's procedures will be implemented in good faith, the hospital's policies must provide for the confidentiality of the identity of, and prohibitions of retaliation against, potential callers who, in good faith and nonmaliciously, provide information about possible noncompliance. A hospital need not, in order to post Notice A, have an Infant Care Review Committee in con-

formance with the model ICRC, nor forego management prerogatives with respect to anyone who might abuse the hospital's procedures by, for example, willfully making false or malicious calls. Hospitals for which the content of "Notice A" is not truthful must post the notice identified as "Notice B."

Second, the requirement regarding the location where copies of the notice must be posted has been changed. Consistent with the Department's intent to target the notice to nurses and other health care professionals, the proposed rule required that the notice be posted at the nurses' stations of appropriate wards, rather than more generally in the wards as had been stated in the March interim final rule. In view of the concern expressed by a number of commenters that posting in the nurses' stations would continue to make the notice conspicuous to distressed parents, the final rules do not require that copies of the notice be posted at nurses' stations. Rather, the notice is to be posted at any location(s) where nurses and other medical professionals who are engaged in providing health care related services to infants will be aware of the content of the notice. Locations such as locker rooms and lounge areas will suffice as long as placement in these locations ensures that the appropriate personnel will see the notice. Under these circumstances the notice would not have to be posted at nurse's stations or any other location where posting would have adverse effects on parents. The number of copies which must be posted in the hospital is similarly determined on the basis of ensuring that the appropriate personnel will see it.

Third, in view of this more specific targeting, the size of the notice has been reduced from the 8½ × 11 inches requirement in the proposed rule (and the 17 × 14 inch notices distributed in connection with the March rule) to 5 × 7 inches.

Fourth, the wording of the informational notice has been revised in connection with the language which attempts to convey in simple terms the basic protection of the law. The new language reflects the law's deference to reasonable medical judgments, refers to "medically beneficial treatment" and clarifies that the concept of handicapped discrimination

relates to decisions made solely on the basis of present or anticipated mental or physical impairments. The reference in the text of the notice and elsewhere in the rules to "present or anticipated mental or physical impairments" is based on the definition of "handicapped person" in existing regulations, 45 CFR 84.3(j). The Department believes this phrase conveys a better understanding than use of the word "handicap."

The Department has also changed the heading of the notice to eliminate what many perceived to be a negative statement. The revised notice adopts the same heading. "Principles of Treatment of Disabled Infants", adopted by the coalition of leading disability and medical organizations in their landmark statement of principles.

In seeking to compose the wording of the notice, the Department has sought to set forth a simple, understandable, and accurate description of the requirement of the law. To a significant degree, the application of section 504 in this context defies a simple and precise restatement. The wording of the notice, however, does not establish a legally mandated rule of conduct; it merely conveys information. In recognition of the impossibility of setting forth a statement that covers all possible dimensions and nuances of the statute, the notice advises that callers may obtain further information by calling the designated contact points.

The Department believes this statement resolves many of the concerns regarding ambiguity of the prior version of the notice without becoming so cumbersome and complicated that it confuses more than it informs.

Concerning other comments, the Department is not adopting the suggestion that hospitals be required to notify HHS that the notice has been posted. There are insufficient benefits accruing from establishing a mechanism for checking off approximately 7,000 unverified notifications of posting to justify the administrative burden on the Department and recipients.

In addition, consistent with the objective of targeting the notice to nurses and other medical professionals, and in view of concerns about frightening parents, the Department is not adopting the suggestion that the nondiscrimination notice be

required on hospital admission or consent forms. However, the Department encourages hospitals and Infant Care Review Committees to consider seriously developing some written information for parents with respect to hospital policies and procedures in connection with this issue. Such information could include an explanation of rights and responsibilities of parents, infants, and hospitals, the operation of the ICRC, available social services, and other pertinent information.

The Department is also not adopting numerous suggestions for additions to the notice because they are unnecessary and would make the notice cumbersome and possibly confusing. Statements concerning the existence of sanctions for noncompliance, the applicability of section 504 to infants born alive after abortions, the lawfulness of withholding futile treatments, and the applicability of section 504 to a wide range of aspects of medical care are all quite correct, but their inclusion in the notice is unnecessary.

The Department is not adopting the suggestion that the notice state that callers are not required to identify themselves. Although the Department will take appropriate follow-up action on anonymous calls that convey credible and specific information, the Department does not wish to encourage callers to remain anonymous because there is great value in having the ability to recontact the complainant as the inquiry or investigation progresses. The Department believes the statements contained in the notice regarding confidentiality of the identity of callers and prohibitions against retaliation are adequate to overcome the understandable reluctance a sincere potential complainant may have.

Finally, although the statement is correct, the Department adopts the suggestion that the reference to violations of state criminal and civil laws be deleted because it is unnecessary and potentially inflammatory.

C. RESPONSIBILITIES OF CHILD PROTECTIVE SERVICES AGENCIES

A number of commenters addressed the provision of the proposed rule requiring that state child protective services agencies establish and maintain written methods of administration and procedures to ensure full utilization of their au-

thorities pursuant to state law to prevent instances of medical neglect of handicapped infants.

Several child protective services agencies and their respresentatives opposed this provision. As stated by the National Council of State Public Welfare Administrators:

> While the NCSPWA agrees there is a need to establish additional protections for infants born with handicapping conditions, * * * we believe the child protective services agency is not, as a rule, the appropriate authority to establish standards for medical treatment, to police the medical profession, or to make the kinds of medical/ethical judgments required in this area.

The State of Nebraska Department of Public Welfare expressed support for increased involvement of state child protective services agencies:

> We feel that the agency with primary responsibility for investigation and enforcement of this law should be the State Protective Services Agency. We further would suggest that hospital administration be charged with the responsibility for reporting any possible violations of this law to the State Protective Services Agency.* * * The State Protective Services Agency should be responsible for reporting to the Office of Civil Rights the results of any actions taken as a result of the report.* * *

Some commenters urged deletion of the requirement that state agencies report cases to OCR because it conflicts with the confidentiality requirements of state child abuse and neglect statutes and presents an unnecessary administrative burden. Other commenters suggested that this requirement be expanded to require reports to OCR at each step of an agency's investigation. Other commenters suggested that state child protective services agencies be required to involve state protection and advocacy systems for the developmentally disabled in all of its activities related to this issue.

Response

Section G, below, includes a discussion of the applicability of section 504 in cases where a refusal to provide medically beneficial treatment is a result, not of decisions by a health

care provider, but of decisions by parents. As explained in that section, it is the responsibility of the hospital in such a case to report the circumstances to the state child protective services agency. If that agency receives Federal financial assistance in its child protective services program, it may not fail, solely on the basis of the infant's present or anticipated physical or mental impairments, to utilize its full authority pursuant to state law to protect the infant. Although there are some variations among state child protective statutes, all have the following basic elements: a requirement that health care providers report suspected cases of child abuse or neglect, including medical neglect; a mechanism for timely receipt of such reports; a process for administrative inquiry and investigation to determine the facts; and the authority and responsibility to seek an appropriate court order to remedy the apparent abuse and neglect, if it is found to exist.

Consistent with the applicability of section 504 to child protective services agencies and with the typical elements of state child protective statutes, the proposed rule included a subsection requiring that, within 60 days of the effective date, "each recipient state child protective services agency shall establish and maintain written methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances of medical neglect of handicapped infants."

This provision was modeled after an existing provision in the Department's regulation implementing title VI of the Civil Rights Act of 1964, 45 CFR 80.4(b), which requires all continuing state programs to have "such methods of administration for the program as are found by the responsible department official to give reasonable assurance" of compliance.

The proposed rule went on to specify several elements which must be included in the agency's methods of administration and procedures. Four of these elements precisely mirror the common fundamental components of state child protective statutes.

The proposed rule also called for immediate notification to the Department of each report of suspected medical neglect of a handicapped infant, the steps taken by the agency to in-

vestigate such report, and the agency's final disposition of such report. This requirement was also based upon an existing regulation, 45 CFR 80.6(b), which requires compliance reports "in such form and containing such information" as the Department may require. Therefore, the proposed rule's requirement for notification to OCR is simply a specification of a type of compliance report the Department deems necessary to monitor the recipient's compliance.

With respect to the comments concerning the potential conflict between this notification requirement and the confidentiality provisions of state child abuse and neglect statutes, this provision is entirely consistent with existing regulatory requirements of recipient child protective services agencies under 45 CFR 80.6(c), which includes the statement: "Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part."

In addition, HHS regulations requiring, as a condition of receiving Federal funds, state child protective services agencies to protect the confidentiality of child abuse and neglect information also make clear that HHS and the Comptroller General of the United States must have access to documents and other records "pertinent to the HHS grant." 45 CFR 1340.14, 74.24.

The Department has not adopted the suggestion that more detailed requirements be established for state child protective services agencies because the requirements should be flexible enough to be easily incorporated into existing agency procedures.

Section 84.55(c)(1) of the final rules adopts the corresponding provision of the proposed rules without substantive change. In summary, it simply restates existing section 504 responsibilities of recipient state child protective services agencies; requires standard procedures to assure compliance (as has been long required for continuing state programs under title VI); specifies the basic elements of those procedures (which precisely mirror the standard components of state statutes); and specifies a form of compliance reports required under existing agency responsibilities. Consistent with the Department's investigative guidelines, § 84.55(c)(2) encour-

ages state agencies to involve Infant Care Review Committees in connection with the agencies' actions pursuant to its state law and procedures.

D. EXPEDITED ACCESS TO RECORDS

The final rules create a limited exception to the Department's existing regulations pertaining to access to sources of information. The existing regulation, 45 CFR 80.6(c), made applicable to section 504 cases by 45 CFR 84.61, states:

> Each recipient shall permit access by the responsible Department official or his designees during *normal business hours* to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part. [Emphasis supplied.]

The proposed rules included a modification to specify that access to pertinent records and facilities of a recipient "shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." The final rules adopt this change in § 84.55(d).

A number of commenters expressed support for the provision as essential to efforts to save lives. Others objected on the grounds that investigations are highly disruptive, the OCR officials are not qualified to make a judgment regarding the degree of danger to the life or health of a handicapped individual and that the rule should specify circumstances warranting access and procedures applicable to investigations after normal business hours.

Response

The Department views this as a minor, technical clarification. Access to recipient facilities and sources of information is required by existing regulations and is essential for the Department to carry out its statutory obligation to determine whether recipients are in compliance with civil rights laws. The provision in existing regulations regarding "normal business hours" is nothing more than a recognition that many recipients conduct their federally assisted programs and activities only during those hours.

The furnishing of inpatient medical services, however, is not a 9:00 a.m. to 5:00 p.m., Monday through Friday undertaking. Rather, the "normal business hours" for nurseries and neonatal intensive care units are 24 hours a day, seven days a week. The Department, therefore, has the authority to seek pertinent records at any time even in the absence of revision. Nonetheless, the Department adopts this change to clarify its authority and recipients' obligations. The objections expressed regarding this provision are substantially the same as objections to investigative procedures generally, and are discussed in section H, below.

This modification makes clear where the circumstances indicate a risk of imminent, irrevocable harm due to suspected noncompliance, the Department will, as it must, initiate immediate action to determine compliance.

E. EXPEDITED ACTION TO EFFECT COMPLIANCE

The final rules include a slight revision to existing regulatory procedures concerning remedies for noncompliance. Existing regulations, 45 CFR 80.8(a) and (d) (made applicable to section 504 cases by 45 CFR 84.61), provide:

> If there appears to be a failure or a threatened failure to comply with this regulation ... compliance with this part may be effected by the suspension or termination of or refusal to grant or to continue Federal financial assistance or by any other means authorized by law. Such other means may include ... a reference to the Department of Justice with a recommendation that appropriate proceedings be brought to enforce any rights of the United States under any law of the United States ... or any assurance or other contractual undertaking....
>
> * * * * *
>
> No action to effect compliance by any other means authorized by law shall be taken until (1) the responsible Department official has determined compliance cannot be secured by voluntary means, (2) the recipient or other person has been notified of its failure to comply and of the action to be taken to effect compliance, and (3) the expiration of at least 10 days from the mailing of such notice to the recipient or other person.

The proposed rule included a provision that the normal requirement of providing 10-days notice "shall not apply when,

in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual." The final rule, in § 84.55(e), adopts this revision.

A number of commenters expressed support for this provision as essential to efforts to save lives; others objected because the rule did not identify standards for waiving the 10-day notice or alternate procedure to be followed.

Response

The Department considers this a minor, technical change. The 10-day notice was designed to facilitate pursuit of informal compliance in circumstances where noncompliance did not imminently threaten lives. The failure to provide nourishment or treatment to a handicapped infant, however, may have such a consequence.

As a matter of legal interpretation, the Department believes the normal 10-day notice rule would, even absent the proposed change, be inapplicable in a case where the government seeks a temporary restraining order to sustain the life of a handicapped infant in imminent danger of death. Such actions would often be for the purpose of preserving the status quo, such as by continuing the provision of nourishment and routine care, pending a more definitive determination of compliance or noncompliance with section 504, rather than "to effect compliance" following a determination of noncompliance. In addition, the Department believes federal judges would be appropriately loathe to allow minor procedural technicalities to defeat totally the accomplishment of the statutory purpose. Nonetheless, the Department proposed this limited exception to the normal 10-day notice rule to clarify its authorities and corresponding recipient responsibilities.

The determination of the need to waive the 10-day notice will be made in accordance with the standard investigative procedures, explained in section H, below. Concerning alternate notice procedures, the final rule provides that oral or written notice will be provided as soon as practicable.

F. GUIDELINES RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS

Most of the comments submitted during the comment period dealt with issues well beyond the specific provisions of the proposed rules, such as the applicability of section 504 to this subject matter and the Department's section 504 enforcement process.

Like the proposed rules, the final rules contain four discrete requirements applicable to recipients of Federal financial assistance. First, hospitals must post an informational notice. Second, the normal 10-day notice before initiating action to effect compliance can be waived when immediate action is necessary. Third, access by the Department to pertinent records and facilities can be obtained after "normal business hours" when immediate access [is] necessary. Fourth, state child protective services agencies must establish procedures to utilize their full authority under state law to prevent medical neglect of handicapped infants.

To bring these specific provisions further back into focus, it is useful to note what the final rules, like the proposed rules, do *not* do. They do not establish the applicability of section 504 to the provision of health care to handicapped infants. The applicability of section 504 is already established by the statute and the existing HHS regulations. They do not establish the authority or procedures of HHS to investigate reports of suspected noncompliance with section 504. Authority and procedures are already established by the statute, existing regulations and administrative practices. They do not establish a toll-free telephone number, which has been established and is in operation. Although most of the controversy concerning the rules relates to the broader issues, the mandatory aspects of the final rules deal only with several discrete points.

Nonetheless, many of the comments relating to the broader issues were highly relevant and valuable. Other comments on the broader issues reflected a lack of understanding of how the Department interprets the applicability of section 504 in this area and the Department's compliance procedures. To clarify these issues, the final rules include an appendix, which sets forth guidelines relating to health care

for handicapped infants. This appendix includes interpretative guidelines relating to the applicability of section 504 and guidelines for HHS investigations in this area. These guidelines do not independently establish rules of conduct or substantive rights and responsibilities, which are established by the statute and existing regulations. The Department will apply these guidelines flexibly to take into account the circumstances presented in each case regarding both the determination of compliance or noncompliance and the conduct of the investigation. These guidelines are set forth as an appendix to the final rules simply to assist recipients and the public in understanding the Department's general interpretations and procedures. This appendix becomes a part of the permanent Code of Federal Regulations.

G. INTERPRETATIVE GUIDELINES RELATING TO THE APPLICABILITY OF SECTION 504

Medically Beneficial Treatment

As stated in the preamble to the proposed rules, the Department interprets section 504 as requiring that medically beneficial treatment not be withheld, solely on the basis of handicap, from a handicapped infant.

Three of the questions on which the July 5 notice of proposed rulemaking specifically solicited comments concerned the issue of medically beneficial treatment as the standard to guide treatment decisions, including further explanations that would assist health care providers and the public in understanding the requirements of section 504, implications concerning cost and the allocation of medical resources, and the impact of perceived economic, emotional and marital effects on parents.

Among commenters supporting the standard of providing medically beneficial treatment was the Down's Syndrome Congress:

> Some children may be unwanted by their parents.... The Down's Syndrome Congress does not seek to judge those parents who do not feel that they can adequately parent because of the handicap. Rather, we seek to make available those adoption homes that want children who have Down's syndrome.

Also typical of comments in support of the standard of providing medically beneficial treatment was the comment of the Association for Retarded Citizens:

> No quality of life or other such considerations are acceptable to the ARC. Although we are primarily a parent organization and many ARC members have had significant difficulty (financial, emotional, etc.) raising their mentally retarded child, we come down strongly on the side of the child.
>
> Available medical and other technology is not able to fully predict the future capacity of most mentally retarded children, especially in the first days and weeks of life. Our members can cite numerous examples of improper and wrong advice given to them by physicians about the future capacities of their children.

A number of commenters argued that the medically beneficial treatment standard is inappropriate. For example, the Department received the following comment from a Texas physician:

> [N]ot only is the "very strict standard" advocated by the President's Commission "not being uniformly followed," [as stated in the HHS July 5 NPRM] it is probably close to *uniformly not* being followed. The "very strict standard" the Secretary of Health and Human Services is trying to foist on the medical community is contrary to the usual practices of that community. (Emphasis in original.)

Similarly, the following comment was submitted by an Alabama physician:

> Recently I have treated a 13-month old black child who has congenital heart disease, spastic encephalopathy, vomiting, repeated bouts of bilateral pneumonia, internal squint of the left eye, and mental deficiency. He is one of the thousands of children who are the victims of the neonatal intensive care units located in every medical center. He was born premature, weighing two pounds and ten ounces. With modern treatment and instruments he survived. These children have no future and are a terrible burden on their parents and this nation.
>
> * * * What good is it treating these premature babies? Will it not be better if they are left to die? * * *

> We are compounding our problems by bringing into life thousands of congentially sick babies which nature has rejected.

A number of commenters, particularly medical organizations, suggested different articulations of standards. For example, the American Medical Association combines a number of notions in articulating the standard to be applied, including consideration of "quality of life", and deference to parental decisions unless there is "convincing evidence to the contrary." The full text of the AMA position is as follows:

> QUALITY OF LIFE. In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

Another articulation of standards, submitted by the Biomedical Ethics Committee of the University of Minnesota Hospitals, includes the following ethical principles:

> When the burden of treatment lacks compensating benefit or treatment is futile, the parent(s) and attending physician need not continue or pursue it.
>
> Therapies lack compensating benefit when: (a) they serve merely to prolong the dying process; (b) the infant suffers from intolerable, intractable pain, which cannot be alleviated by medical treatment; (c) the infant will be unable to participate even minimally in human experience.

Probably the most poignant comments regarding the standard which should be applied relating to the provision of medical care to handicapped infants were submitted by parents of handicapped children. Of 100 commenters who identified themselves as parents of handicapped persons, 95 supported the proposed rule and five opposed it. From a Montana mother:

> My daughter Keough was born in November 1980 with Down's syndrome and a host of birth defects in her digestive system similar to Baby Doe's problems * * * Twenty minutes after her birth our then pediatrician offered to let her starve in the hospital nursery* * *
>
> * * * * *
>
> * * * There are times when I am getting up for the tenth time during the night to suction my daughter's trach tube so she can breathe that I would give anything not to have to deal with the situation, but I will never regret having her as part of the family.

From a mother and father, both physicians, in California:

> [A]s the parents of an eight-year-old boy with Down's Syndrome, who suffers from marked retardation and a severe cardiopulmonary condition, we do appreciate both the deep anguish and the countless joys that derive from caring for and caring about a severely handicapped child. There is no limit set on the strength, the growth and the fulfillment that his love continues to bring us every day. For his sake and for the sake of all the handicapped newborn, it is urgent that safeguards be enacted. Let merciful caring, not mercy-killing, be our answer to their needs.

Another dimension of the comments concerning the interpretation of section 504 as requiring that medically beneficial treatment not be withheld solely on the basis of handicap re-

lates to the difficulty of determining the "medically beneficial treatment." As stated by the Children's Hospital of Boston:

> [The NPRM] states that the denial of treatment where there is no medical benefit to the individual would not be discriminatory because the individual would not be a "qualified handicapped person" within the meaning of section 504. [A problem with this analysis is that] it relies on outcome which cannot always be predicted or, even if predicted is not always accurate, may be affected by other factors, and may not even be known for an indeterminate time. If section 504 is to provide guidance in treatment situations, its applicability should be known at the outset. Otherwise staff will be subject to an after-the-fact scrutiny which may well be inaccurate and oppressive.

Another comment regarding the role of medical judgments was submitted by presiding Judge John G. Baker, Monroe Superior Court, Division III, the Judge who decided the Bloomingtom Infant Doe case:

> The question in the Infant Doe case was, when parents are confronted with two competent medical opinions, one suggesting that corrective surgery may be appropriate and the other suggesting that corrective surgery and extraordinary measures would only be futile acts, does the law allow the parents to select which medical course to follow? It was the decision of the Indiana Court that the law provided the parents with the responsibility of choosing which medical course to follow without governmental intervention.

Response

The Department's position remains unchanged. Section 504 provides:

> No otherwise qualified handicapped individual shall, solely by reason of his handicap, be excluded from participation, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance...

The statute defines a "handicapped individual" as:

> Any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities ... or (iii) is regarded as having such an impairment.

A key issue in applying section 504 in any context is that the handicapped individual who is allegedly excluded from participation in, denied the benefits of, or subject to discrimination under a federally assisted program or activity be "otherwise qualified" to participate in, or benefit from, the program or activity, in spite of his or her handicap. In the context of receiving medical care, the ability to benefit for a handicapped person is the ability to benefit medically from treatment or services. If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's present or anticipated physical or mental impairments, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that health care providers may not, solely on the basis of present or anticipated physical or mental impairment of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

Not only is this analytical framework directed by the statute, the Department believes the medically beneficial treatment standard is the appropriate guiding principle for providing health care services to handicapped infants. The Department agrees with the President's Commission that "it is all too easy to undervalue the lives of handicapped infants," and that it is "imperative to counteract this" by excluding "consideration of the negative effects of an impaired child's life on other persons" and to treat handicapped infants "no less vigorously than their healthy peers."

The Department also agrees with the essential principle contained in the joint statement of November 29, 1983, by the coalition of medical groups and the disability organizations, including the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, the association for Retarded Citizens, the Spina Bifida Association of America, and others:

> When medical care is clearly beneficial, it should always be provided.... The individual's medical condition should be the sole focus of the decision.

Consistent with the recommendations of the President's Commission and the principles agreed to by the coalition of medical and disability groups, paragraphs (1), (2) and (3) of section (a) of the appendix state the basic interpretative guidelines of the Department for applying section 504 in this context. These interpretative guidelines make clear that health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant, who, in spite of such impairments, will medically benefit from the treatment or nourishment. They also made clear that futile treatments or treatments that will do no more than than temporarily prolong the act of dying of a terminally ill infant are not required by section 504, and that, in determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected. The principle of respecting reasonable medical judgments reflects the Department's recognition that in many cases the process of medical decisionmaking is not mechanical and precise. Analyses of medical risks, medical benefits, possible outcomes, complications, and the like require experience and judgments. Most of all, they must be specifically based on the actual circumstances presented in any given case. The statutory framework does not provide for, nor will the Department seek to engage in, second-guessing of reasonable medical judgments regarding medically beneficial care.

The principle of respecting reasonable medical judgments in the context of applying section 504 is also consistent with analogous case law. For example, the Supreme Court has made it clear that the application of constitutional protections do not interfere with *bona fide* medical judgments so as to authorize a court "to specify which of several professionally acceptable [treatment] choices should have been made." *Youngberg* v. *Romeo*, 457 U.S. 307, 321 (1982).

However, the Department also recognizes that not every opinion expressed by a doctor automatically qualifies as a reasonable medical judgment. For example, a doctor's opinion that available corrective surgery to save the life of a Down's syndrome infant should be withheld is contrary to

the opinion of the President's Commission and comments submitted to the Department by the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and other medical organizations. It is not within the bounds of reasonable medical judgment and is not entitled to deference.

Parental Decisions

A number of commenters argued that the Department's analysis of section 504's applicability fails to take into account the lack of authority hospitals and physicians have to perform treatment to which the parents have not consented. Some commenters expressed a belief that the Department purports to require physicians and hospitals unilaterally to overrule parental decisions. As stated by the American Medical Association:

> If section 504 is applied as the Department claims it should be, physicians and hospitals will be required to treat a handicapped infant in all cases, regardless of parental consent, for fear of sanctions allegedly authorized by section 504.

Similarly, the National Association of Children's Hospitals and Related Institutions stated:

> Nor does the rule recognize that, in lieu of indications to the contrary, decisions of care of the infant made by these parents, based on their determination of the child's best interest, are theirs to make, a right and responsibility assigned to them universally by state statute....

Also in connection with the issue of a recipient's section 504 responsibilities in cases where parents refuse to consent to medically beneficial treatment, a number of commenters criticized a statement included in the Department's May 18 notice to health care providers that:

> Health Care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

The criticism was that to discharge the infant, as the statement implied the hospital should do, would be unlikely to ad-

vance the objective of assuring that the infant receive medically beneficial treatment.

Response

The Department's position has been, and continues to be, that the lack of parental consent does have an impact on a recipient hospital's section 504 responsibilities, but that the lack of parental consent to provide particular treatment does not remove from hospitals the obligation to operate other aspects of their program without discrimination.

Although the need may not arise frequently, it is an accepted part of the operation of hospitals to contest the denial of parental consent when such a decision is not in the best interest of a child. Most hospitals have established procedures to petition courts to order medical care when parents do not provide consent for treatment that is medically needed and appropriate.

In addition to the internal hospital procedures, state laws generally establish responsibilities of health care professionals where treatment is being withheld because of improper denial of parental consent. Health care professionals are generally required by state law to report cases of abuse, neglect, or other threats to a child's health. These laws, whether explicitly or implicitly, include the denial of needed medical treatment as an event requiring reporting.

The requirement that health care providers report instances of improper denial of medical care is no less a part of their program than is the provision of care itself. Both arise from the recipients' program of administering to the medical interests of its patients. Section 504 prohibits discrimination on the basis of handicap in the operation of federally assisted programs and activities. Thus, a recipient that, as a matter of practice or law, reports to State authorities the withholding of needed medical treatment from an infant may not deny the same service or benefit to a qualified handicapped infant because the infant is handicapped.

Section 504 applies only to programs or activities receiving federal financial assistance; it does not apply to decisions made by parents. Where a nontreatment decision, no matter how discriminatory, is made by parents, rather than by the

hospital, section 504 does not mandate that the hospital unilaterally overrule the parental decision and provide treatment notwithstanding the lack of consent. But it does require that recipient hospitals not fail, on the basis of handicap, to report the apparently improper parental decision to the appropriate State authorities, or to seek judicial review itself, so as to trigger the system provided by State law to determine whether the parental decision should be honored. Action by hospitals to seek judicial review is not uncommon in cases where, for example, parents have objected on religious grounds to a medically necessary blood transfusion for their child.

The Department agrees with the criticism of the sentence in the May 18, 1982 notice. This statement reflected a recognition by the Department that section 504 does not require hospitals unilaterally to overrule parental decisions, and that hospitals cannot provide treatment without parental consent. The point should have been better stated that a recipient hospital may not blindly implement improper and discriminatory parental decisions. Rather, the hospital should resort to the system provided by state law to determine whether a parental decision should be implemented.

Therefore, the proper analysis of the applicability of section 504 in cases where the failure to provide medically indicated treatment is due to a lack of parental consent is that a recipient hospital is not required to seek to unilaterally overrule the parents, but it must adhere to the standard practice, as required by state law, to make a report to the state agency charged under state law with responsibility to initiate the determination as to whether the parental decision was proper, or to seek judicial review itself. This interpretative guideline is set forth in section (a)(4) of the appendix.

Rather than representing an improper Federal government attempt to "question and overturn the decisions of parents concerning their children's medical treatment," the Department is simply requiring that the long-standing requirements and mechanisms of *state* law for defining the limits of parental authority not be rendered, through discriminatory actions of recipient hospitals, *de facto* inoperative.

Examples

The July 5 proposed rule was accompanied by an appendix explaining the manner is which section 504 applies to the provision of health care services to handicapped infants and providing several examples of its applicability to particular factual situations. A number of commenters criticized statements contained in that appendix. Criticisms and comments were as follows: (a) Use of phrases such as "futile therapies", "services generally provided", and "dubious medical benefit" are ambiguous. (b) The characterization of infants with intracranial hemorrhage as analogous to anencephaly is incorrect. Intracranial hemorrhages vary greatly in severity, and are generally treatable and treated. (c) The American Society for Parenteral and Enteral Nutrition stated that although there are no circumstances justifying "withholding oral feeding through a working digestive tract in any patient capable of digesting food, in whole or in part," there may be "limited circumstances" in which not providing nourishment through intravenous means "may be appropriate." (d) The appendix does not indicate the appropriate care for infants who have conditions with prognoses worse than Down's syndrome but less severe than anencephaly, such as Trisomy 18, Trisomy 13, Holoprosencephaly, Hydranencephaly, Cornelia de Lange Syndrome, and many others.

(e) "It would be impossible to develop a complete list be handicaps to which the regulations apply. The limited ability to predict outcomes, and the rapid changes in diagnostic and therapeutic modalities make such a goal wholly impracticable."

Response

The application of constitutional and statutory civil rights protections in scores of contexts is difficult. A glance at the Supreme Court's docket confirms this, as every year difficult issues are presented to the Court for resolution. These cases often produce split decisions and multiple opinions.

Therefore, it is to be expected the definitive statements on various dimensions of the applicability of the handicapped discrimination law in connection with health care for handicapped infants, a subject no less difficult than many other as-

pects of civil rights law, would be few. The imprudence of seeking to speculate on the outcome of applying section 504 in a wide variety of specific factual circumstances was underscored by some of the comments received.

Keeping in mind the utility of providing some examples to assist in understanding the analytical framework of the statute, but also the need to allow individualized attention to specific factual circumstances, the guidelines included in the appendix (section (a)(5)) set forth examples dealing with Down's syndrome, spina bifida, anencephaly, and extreme prematurity.

The Department agrees with the comment that it would be impossible to establish a specific list of all handicapping conditions and the proper treatment in each case. None of the commenters who perceived ambiguities had convincing answers to the questions they raised.

It is appropriate that the law (and thus the government) does not prospectively and unequivocally answer every hypothetical question. In many cases, the law, like medical treatment, can only be applied on a case-by-case basis with a full appreciation for the facts presented.

But it is also appropriate that the law and government have an analytical framework for approaching the issue and a procedural framework for seeking, in cooperation with the medical community and advocacy groups, to narrow the "gray area." The final rules seek to do no more, and importantly, no less.

H. GUIDELINES FOR HHS INVESTIGATIONS RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS

Conduct of Investigations

The July 5 notice of proposed rulemaking solicited comments on HHS investigative procedures. A number of commenters argued that OCR complaint investigations are highly disruptive. The primary concerns expressed in this regard were:

(a) Due to the complexity of the subject matter, there are many erroneous complaints, either by well-intentioned, but ill-informed, persons or by disgruntled employees.

(b) Anonymous calls are not reliable.

(c) Investigations monopolize the time of physicians, nurses and other hospital staff, and make medical records, while under review by OCR investigators, unavailable.

(d) Investigations carry with them the potential for sensational media coverage, which can unjustly damage the good reputations of parents, hospitals and health care professionals.

(e) The presence of OCR investigators is likely to frighten other infants' parents who will assume that, because investigators are present, the hospital must be guilty of improper conduct.

Response

Although some potential for inconvenience or disruption exists in connection with any type of law enforcement investigation, because of the traumatic circumstances of an infant's illness, the potential for sensationalistic media coverage, and other factors, the Department is very sensitive to the special nature of "Infant Doe" investigations. As HHS has gained experience in conducting these investigations, revisions to investigative procedures have been implemented to minimize any disruptive effects. It is the policy of the Department to do everything possible, consistent with its statutory obligation to investigate effectively all complaints of violations of section 504, to minimize any disruptions that may be caused by OCR investigations.

OCR has made adjustments to investigative procedures. It now undertakes a careful screening of complaints in an effort to avoid unnecessary on-site investigations. This screening consists of immediately initiating a preliminary inquiry with the hospital to obtain information regarding the infant in question. The information initially received from the complainant and that received from the hospital is then evaluated to determine whether there is a need for an on-site investigation. Particular factors taken into account are the source of the complainant's information (first-hand knowledge, overheard a discussion, etc.), the complainant's position to have reliable information (a nurse in the ward where the infant is being treated, a friend of a friend, etc.), the specificity of the information provided by the complain-

ant and hospital, whether there is any indication of a lack of parental consent for the provision of all medically beneficial treatment, the analysis of the ICRC, whether the hospital is cooperative in connection with the inquiry, and other pertinent factors.

None of these factors considered in evaluating the information provided by the complainant and the hospital is, by itself, determinative. For example, the Department prefers that the complainant provide his or her name. Not only does it corroborate that the complainant takes the matter seriously and reflects some degree of confidence the complainant has in the accuracy of the information being conveyed, having the complainant's name also permits follow-up communications to seek clarification of the information gathered. However, the Department recognizes that a complainant may not be willing to provide his or her name due to fear of retaliation, and the anonymity does not necessarily suggest that the complaint is not valid, particularly if the specificity of the information provided and other factors support the credibility of the complaint. Therefore, the determination as to whether an on-site investigation is needed is made on the totality of the information available to OCR from the complainant, the hospital, and any other source consulted (such as an OCR medical consultant and the state child protective services agency).

HHS believes this procedure, if hospitals cooperate in its implementation, can avoid unnecessary on-site investigations, which inherently have a potential for some inconvenience. Although hospital officials may be properly reluctant to provide information over the telephone, they can confirm the credentials of the OCR investigator making the telephone contact by calling the toll-free telephone number to verify that the caller is, in fact, an OCR investigator.

Where, as a result of this preliminary inquiry, there appears to be no need for an immediate on-site investigation, none will be conducted. However, to assure that HHS is adequately meeting its statutory responsibility, where there is a significant question as to compliance with section 504, doubt will be resolved in favor of initiating an on-site investigation.

This preliminary inquiry process is undertaken by OCR in an effort to accommodate the special circumstances presented in connection with "Infant Doe" complaints. This procedure should not be construed as suggesting that the Department believes there are any limitations to its legal authority to investigate all complaints or to otherwise collect information regarding recipient compliance in accordance with the Department's existing section 504 regulations. Nor does this preliminary inquiry process establish any legally enforceable procedural right or precondition to the conduct of on-site investigations.

When on-site investigations are conducted, OCR's procedures minimize any potential inconvenience or disruption. Every effort is made, consistent with the need to obtain prompt information, to accommodate the busy schedules of health care professionals to avoid diverting them from their important duties. Similarly, OCR has never had a problem working out access to medical records to avoid their being unavailable to health care professionals who also need access to them.

With respect to media interest, OCR has a firm policy of providing no comment to the press on the details of any open investigation. HHS believes organizations or individual complainants concerned about proper patient care should be extremely sensitive to threats to proper care inherent in making premature and unsupported comments to the media. Similarly, the media should be attentive to OCR's admonition, regularly given in response to media questions, that the fact that an investigation is being conducted does not imply that an allegation is true.

Section (b)(1) through (5) of the appendix spell out the basic guidelines, including the preliminary inquiry process, applicable to HHS investigations in this area. These guidelines make specific reference to the role of Infant Care Review Committees. Whenever a hospital has an ICRC, established and operated substantially in accordance with the suggested model, the Department will consult closely with the ICRC in connection with a preliminary inquiry or investigation and will give careful consideration to the analysis and recommendations of the ICRC.

The Department believes OCR procedures, including the initial inquiry process, minimize the potential for disruption. HHS will, on the basis of further experience gained, such as with ICRCS, continue to evaluate its procedures consistent with the policy of effective enforcement with a minimum of disruption. The Department also notes that there is probably an irreducible level of inconvenience associated with any effort to provide safeguards to prevent the fatal consequences of discriminatory decisions. It must be recognized, however, that the risks of a certain amount of inconvenience or disruption are significantly preferable to the risks of tragic loss of life due to discriminatory decisionmaking.

Use of Medical Consultants

Another concern expressed by commenters relates to the qualifications of the individuals involved in the administrative fact finding process to evaluate correctly the medical circumstances present in any particular case. For example:

> The Alabama Hospital Association strongly feels that the [investigative] team should be comprised of highly trained and licensed medical personnel. Under no circumstances should anyone less than licensed medical personnel be allowed to intrude in this area of medical decisionmaking and impose alternative judgments or conclusions.

The Spina Bifida Association of America made a similar comment from a different perspective:

> The key to effective enforcement is securing an independent medical examination of children allegedly being denied treatment, by a physician or medical team both skilled in modern treatment techniques *and* committed to the equal treatment principle. Such physicians do exist, particularly at expertise centers that have specialized in the care of children with spina bifida. The only way to ensure effective enforcement is to give disability rights groups like SBAA the ability to recommend *which* expertise centers and expert consultants are used by the regional OCR offices to conduct the independent medical examinations.

Response

HHS agrees that OCR investigators do not have the medical expertise to make independent judgments concerning difficult medical issues. For this reason, the Office for Civil Rights has made arrangements with qualified physicians to serve as medical consultants to OCR in "Infant Doe" investigations. This process is noted in section (b)(6) of the appendix.

The role of the OCR medical consultants is to provide OCR with an analysis of the medical issues present in any particular case, and an opinion as to whether medically beneficial treatment was provided. Based on this analysis, OCR makes a determination as to whether any medically beneficial treatment may have been discriminatorily denied solely on the basis of the infant's handicap.

The extent of the involvement of the OCR medical consultant has varied depending upon the circumstances of particular cases. In all cases the OCR medical consultant reviews the pertinent medical records. In some cases the OCR medical consultant and the attending physician have discussed a case by telephone. HHS believes the experience to date with OCR medical consultants demonstrates the effectiveness of their involvement. HHS is aware of no case in which a recipient has challenged the quality of the medical consultant's evaluation or the OCR findings based upon it.

It is important that all interested groups understand the precise and limited role of the OCR medical consultants. Their function is *not* to take over the medical management of particular cases, to conduct a personal, independent examination of the infant, to make independent treatment recommendations to parents, or to otherwise engage in any direct practice of medicine concerning the infant.

The Department has no authority to compel unilaterally an independent medical examination of a child who is the subject of a section 504 complaint. Under applicable requirements of law, physicians may not practice medicine on an infant patient without the consent of the parents or an order of a court of competent jurisdiction.

In any given case, any of a wide variety of circumstances may be present regarding the actions of parents and health care providers. Regardless of the circumstances, the first step is to determine the facts. Only if the facts demonstrate that there is a need for governmental action can that action be pursued. A court will only issue an order if there is a showing of a need for the order, such as evidence that the hospital *is* out of compliance with section 504 or showing that the parents *are* medically neglecting the infant. Such a showing cannot be made on the basis of the bare allegations of a complaint or without a determination of the facts.

OCR's function in an investigation is to determine the facts, and the function of the medical consultant is to assist OCR in this effort. The process of determining the facts typically involves a review of medical records and discussions with health care providers involved. The OCR medical consultants assist in this process by providing identification and expert analysis of the medical issues involved. These consultants do not, and may not under applicable law, take over the medical management of the case.

With respect to the suggestion that HHS give disability groups the opportunity to recommend qualified physicians to serve as OCR medical consultants, the Department would welcome such suggestions from all interested groups.

The Department is unable to commit itself to having a medical consultant participate in person in every on-site investigation. However, the guidelines contained in the appendix state that, to the extent practicable, the OCR medical consultant will discuss the case with the hospital's ICRC or appropriate medical personnel by telephone.

Prompt Report of Investigative Findings

Another complaint made by a number of commenters regarding OCR enforcement procedures concerns the sometimes lengthy delay between completion of the on-site investigation and receipt by the hospital of notification of the outcome of the investigation. Commenters expressed concern that, particularly in connection with investigations that may have attracted local media attention, where the OCR investigation found no evidence of a violation, the hospital

should have the ability to reassure the public promptly that it was involved in no improper activity.

Response

The point is well taken. Office for Civil Rights procedures pertaining to all investigations require that before the office makes an official finding, whether it is of compliance or noncompliance, a thorough record is complied and reviewed by supervisory officials. Experience in connection with "Infant Doe" cases is that formal findings have been made in less time than is typical in connection with other civil rights investigations. However, there is generally a need for careful review by an OCR medical consultant, an HHS attorney, and supervisory officials.

The Department recognizes that there are special circumstances in connection with Infant Doe cases, and is instituting a special notification to recipient hospitals in cases where an emergency on-site investigation has been conducted. As a matter of practice, on-site investigation of complaints alleging that an infant's life is in peril due to the discriminatory withholding of medically beneficial care are conducted immediately for the primary purpose of determining whether there is a need to ask the Department of Justice to seek immediate injunctive relief to compel compliance with section 504. Generally, during the course of the investigation, when sufficient information has been obtained and discussed with the OCR medical consultant, a decision is made on whether there is such a need.

The new procedure is that, when a decision is made that there is no need to make an immediate referral to the Justice Department, the recipient hospital will be immediately notified of that decision. The investigator will, if still on-site, personally notify hospital officials. A letter to the same effect will then promptly be sent by OCR. This letter will notify the recipient hospital of the decision made concerning immediate referral to the Justice Department. It will not provide a formal finding concerning the investigation, which cannot be made until all information is analyzed and reviewed. (It may be, for example, that, although there is no

emergency requiring immediate legal action by the Justice Department, there is, or was, noncompliance.)

The Department believes this immediate notification procedure, stated in section (b)(7) of the appendix, will provide a basis for the hospital to assure the press and public that OCR's initial conclusion in connection with the investigation is that no infant is in imminent peril due to discriminatory withholding of medically beneficial treatment.

Confidentiality of Records

A number of commenters criticized the enforcement process on the grounds that it infringes on the confidentiality of the physician-parent relationship and the privacy of medical records. Some of these commenters referred to the confidentiality requirements of state law and professional ethical standards.

As stated by the Federation of American Hospitals:

> The physician may be required to inform the parents that anything they may say or decide must be disclosed to federal or state authorities if an investigation results. [P]arents will find that they have a choice between sharing vital information and counseling with their physician and having their thoughts and emotions revealed to a stranger or, alternatively, withholding information.

A suggestion for an additional confidentiality safeguard, submitted by the director of nursing of a Butte, Montana hospital, was to limit review of records to one investigator, on-site, with no copies made.

Response

HHS believes there is no sound legal basis to challenge the Department's right to access to medical records for the purpose of determining compliance with section 504, and that adequate safeguards exist to protect the confidentiality of records obtained by OCR in the course of civil rights investigations.

With respect to legal authority, a state law, such as one restricting access to certain records, cannot, under the Supremacy Clause of the United States Constitution, be used to prevent accomplishment of the full congressional purpose of a Federal law. Similarly, standards of particular profes-

sional groups may not frustrate or defeat a Federal statutory duty.

Section 504 establishes certain responsibilities of recipients and authorizes and directs Federal agencies to enforce the law. Existing regulations, 45 CFR 80.6(c) (made applicable to section 504 by 45 CFR 84.61), require:

> Each recipient shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this Part.... Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this Part. Information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed except where necessary in formal enforcement proceedings or where otherwise required by law.

The requirement that recipients provide access to records necessary to determine compliance is essential to accomplishment of the congressional purpose in enacting section 504.

HHS has adequate safeguards to protect the confidentiality of medical records obtained during the course of a section 504 investigation. In addition to the regulatory provision (quoted above) protecting confidentiality, OCR does not release confidential information in connection with any Freedom of Information Act request. Nondisclosure is permitted under that Act for records, the release of which would constitute a clearly unwarranted invasion of personal privacy. As further protection, OCR permits deletion of the patient's and parents' names and other identifying information to the extent deletion will not impede OCR's ability to determine compliance.

The argument that the possibility that investigators will seek access to a medical file will cause parents to withhold vital information from the infant's physician is not persuasive. Courts and legislatures have repeatedly rejected arguments that exceptions to the principle of confidentiality of medical records and the physician-patient privilege would result in the withholding of information necessary to facilitate

proper treatment. There are many established exceptions in the law to the principle of doctor-patient confidentiality in connection with criminal and civil proceedings where the effective administration of justice requires access to information in medical records or provided to physicians. It is also noteworthy in this regard that the Federal Rules of Evidence do not include an express doctor-patient privilege.

With respect to the suggestions for additional safeguards submitted by a commenter, OCR has in some cases been able to limit review of records to one individual at the hospital, without the need to obtain copies. However, no assurances can be made that OCR can meet its responsibility to conduct a thorough investigation under these conditions. Also, in many cases it may be preferable for the hospital to send OCR the pertinent records (with identifying information deleted), perhaps avoiding the need for any on-site investigation.

IV. RELATED HHS ACTIVITIES

HHS has undertaken several other initiatives in cooperation with the medical community and disability organizations to improve the delivery of health care services to handicapped infants. Recently, a contact was awarded by the Office of Human Development Services, HHS to the John F. Kennedy Institute in Baltimore to develop a model for a working nationwide referral network for the developmentally disabled. Such a network, using today's sophisticated technology, will make it possible for the physician, parents, or care-takers of a developmentally disabled individual to query a single source for information about that disability and pinpoint the best or most appropriate places to get help any where in the country for that individual.

Under the terms of this award, the strong features of two important information systems are to be combined and regionalized. One is a data retrieval system for the particular use of practicing physicians. The other is accessible by the general public. The data base for the physician-oriented system was developed by the Kennedy Institute in Baltimore, using data supplied by the 38 HHS supported university-affiliated facilities around the country. The Amer-

ican Medical Association has a contract with the Kennedy Institute to include the Institute's data as an additional offering of the A.M.A.'s nationwide medical information network, or "MINET." It is available to every "MINET" subscriber who has a desk-top computer and a telephone.

This enterprise pulls together government, the private nonprofit sector, and organized medicine, in this case, the A.M.A., to make information available to physicians concerning access to specialized care for their patients and as well as to a broad variety of support services in the community.

The more consumer-oriented data system is now functioning in South Carolina to benefit the citizens of that state. The system carries information on access to care and community support services within the state. Any individual or family member can gain access to the system merely by dialing a toll-free "800" number.

The Kennedy Institute has an excellent concept of how such a network will function. Under the contract recently awarded, it is hoped the South Carolina Model will be expanded to seven other states in the region. The next step should then be to extend the system nationally and thus make available to all citizens the best information and the most appropriate resources relative to handicapping conditions.

The availability of such a resource should do much to take the insecurity out of one effort to rally support services for the handicapped newborn.

In addition to this nationwide referral network, HHS and the Department of Education, in cooperation with the coalition of medical and disability organizations who signed the "Principles of Treatment of Disabled Infants," are organizing an effort to develop teaching models for health care professionals on improving infant care, aiding the decision-making process and use of the nationwide referral network.

The Department believes that informational and educational efforts of this kind are also of great importance in advancing the principles underlying the final rules.

V. ADDITIONAL ANALYSIS OF COMMENTS

Section III above includes an explanation of the provisions of the final rules, including an analysis of pertinent comments submitted to the Department during the comment period on the proposed rules. This section is an analysis of other comments not directly related to specific provisions of the final rules.

A. LEGAL ISSUES

A significant number of commenters addressed legal issues relating to the application of section 504 to matters concerning health care for handicapped infants.

Statutory Construction of Section 504

A number of commenters argued that, as a matter of statutory construction, section 504 of the Rehabilitation Act of 1973 is inapplicable to matters concerning health care for handicapped infants. The arguments advanced by these commenters were:

(a) The statute does not specifically mention handicapped infants, and the statutory definition of "handicapped individual" should be construed as inapplicable to infants because its reference to substantial limitations on major life activities has no application to infants since all infants are dependent on the efforts of others for performance of all external life activities.

(b) The legislative history makes no mention of handicapped infants and indicates that the primary focus of Congress in enacting the Rehabilitation Act was matters relating to vocational rehabilitation, rather than medical matters; and although the statutory definition of handicapped individual was amended in 1974 to broaden its scope beyond vocational rehabilitation, including access to services such as medical care, there was no indication that the statute, as amended, was intended to cover medical judgments about the type of treatment given any handicapped individual. As stated by one commenter:

> There is not even a hint in the legislative history of the Act or its amendments that would indicate Congressional intent to apply section 504 to medical treatment

of severely handicapped infants. Rather, it is clear that Congress intended the Act to foster fruitful and independent living for handicapped individuals.

(c) The rulemaking history of the Department's section 504 regulations reveals previous HHS interpretations that section 504 is inapplicable.

Response

The Department's position remains unchanged. Section 504 clearly applies to matters concerning the provision of health care to handicapped infants, and nothing in the legislative history of the statute or rulemaking history of the Department's regulations suggests a credible interpretation to the contrary.

Section 504 provides:

> No otherwise qualified handicapped individual... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance....

The statute defines a "handicapped individual" as

> any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities,... or (iii) is regarded as having such an impairment.

An infant is a person. If an infant has a physical or mental impairment which substantially limits major life activities, or is regarded as having such an impairment, the infant is a "handicapped individual" within the meaning of the law. If a hospital engages in a program or activity which provides medical services to infants and if that program or activity receives Federal financial assistance, it is a "program or activity receiving Federal financial assistance" within the meaning of the law.

If an infant who is a "handicapped individual" is "otherwise qualified" to receive the benefits of a medical services program or activity receiving Federal financial assistance, and is denied, solely by reason of his handicap, the benefits of those medical services, that infant is within the protection of section 504.

A key issue, therefore, in applying section 504 in any context is that the handicapped individual who was allegedly excluded from participation in, denied the benefit of, or subjected to discrimination under, a federally assisted program or activity be "otherwise qualified" to participate in, or benefit from, the program or activity. To be "otherwise qualified," the handicapped individual must, in spite of his or her present or anticipated physical or mental impairment, be able to meet the essential requirements for participation in the program or activity.

In the context of receiving medical care, the ability to benefit for a handicapped person is the ability to benefit medically from treatment or services. If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that medically beneficial treatment and services not be withheld from a handicapped infant solely on the basis of the handicap.

The legislative history makes clear that by enacting section 504 Congress intended to eliminate all of the "many forms of potential discrimination" against handicapped people through "the establishment of a broad governmental policy." S. Rep. No. 1297, 93d Cong., 2d Sess. 38 (1974). The statute applies to all federally funded programs or activities, specifically including those that provide "health services." *Id.*

The rulemaking history related to the 1977 promulgation of the Department's section 504 regulations explained that the Department was not seeking to regulate with respect to the highly controversial issue of the rights of institutionalized persons to receive treatment for the condition which led to their institutionalization. Additionally, the regulation specifies that the provision of health care services generally to handicapped persons is a matter covered by the Act and the Department's rules. 45 CFR 84.52.

It is difficult to understand the theory of statutory construction that would distinguish the provision of health care services to qualified handicapped infants from the provision of other federally assisted benefits and services to qualified handicapped individuals.

The Department cannot subscribe to the theory that the definition of "handicapped individual" should be construed as inapplicable to infants because infants are dependent upon others for all major life activities. This argument appears to be based on a much too narrow view of what constitutes "major life activities." The Department's section 504 regulations define "major life activities" at 45 CFR 84.3 (j)(2)(ii), as: "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." Infants undertake at least some of these major life activities from the moment of birth.

Moreover, if this is the theory, the Department is unaware of the basis to be used in determining at what age the protections of section 504 would begin to apply.

In summary, the Department can find no clue in any bit of legal analysis or rational policy analysis to commend the notion that there is or should be a distinction in the application of section 504 based on the age of the handicapped individual.

It appears the real basis for the contention that section 504 is inapplicable in this context is that medical care is involved, rather than what some may perceive as much less complicated matters like distributing welfare benefits, developing transportation systems, administering housing programs, delivering social services, providing educational services, making employment decisions, and the like.

The Department agrees that matters relating to the provision of medical care are in some ways different from other aspects of applying section 504. For one thing, the consequences of discriminatory treatment may be much higher—a matter of life and death. Also, the analysis involved in determining whether discrimination exists may, in some cases, be much more subtle and difficult. But one aspect that appears the same in all applications of section 504 is that decisions regarding whether handicapped persons will receive the serv-

ices and benefits of programs and activities receiving Federal financial assistance are sometimes made, not on the basis of the individual's actual qualifications for, and ability to benefit from, those activities, but rather on stereotypes and prejudices concerning the limitations on major life activities faced by handicapped persons. Section 504 was enacted to eliminate these considerations from such decisions. And although the section 504 analysis may be more subtle (at least in some cases), it is an anomalous and bizarre theory that section 504 can properly be used to require that a ramp be built in a hospital to assure that handicapped persons not be denied access to medical services solely on the basis of their handicaps, but that statute may not properly be used to prevent the intentional act of allowing other handicapped persons to die in that hospital, solely because of their handicaps. The Department cannot subscribe to this theory.

In summary, the Department's position is unchanged. Section 504 clearly applies to the provision of health care for handicapped infants.

Separating the "Handicap" from the Condition Requiring Treatment

A number of commenters expressed views that the section 504 analysis summarized above is incapable of application in many or most cases because the handicapping condition and the condition requiring treatment are one and the same. This fact, the commenters argue, results in an inability to separate "medical judgments" from judgments relating to social, emotional, economic, or other nonmedical issues, concerning which unreasonable prejudices have often caused discrimination against handicapped individuals.

Response

Although perhaps subtle, the analysis required by the statutory framework is just as applicable in a case where the handicapping condition and the condition requiring treatment are the same as it is to the "simpler" case where two distinct conditions are involved.

In the "simple" case involving two distinct conditions, such as Down's syndrome and an intestinal obstruction, the Down's syndrome does not present a medical contraindica-

tion to surgical correction of the intestinal obstruction. There is no valid medical reason (assuming no other condications) for treating the Down's syndrome infant differently than an infant with the same intestinal obstruction and no Down's syndrome.

The same analysis applies where the handicapping condition and the condition to be treated are the same. In such a case the "handicap" is the physical or mental impairment the infant has or will have (or "is regarded as having") *after* completion of the treatment under consideration. In the case of an infant born with myelomeningocele, for example, the treatment which must be considered is surgery to close the protruding sac to prevent infection and other potentially fatal consequences. The "handicap" is the physical and/or mental impairment the infant is regarded as likely to have in future life. To the extent the myelomeningocele itself or other complications (such as respiratory problems, infection, anesthetic risk, or other factors) present, in the exercise of reasonable medical judgment, contraindications to the surgery, the infant is not able to benefit, in spite of his or her handicap, from the surgery. However, if the surgery would be medically beneficial, in that it would be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding infection or other fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is *because* of the handicap and *in spite of* the infant's being qualified to receive the surgery.

In both the Down's syndrome and myelomeningocele examples, this analytical framework accomplishes precisely what Congress intended in enacting section 504: to overcome stereotypes and prejudices against handicapped persons who are, in spite of their handicaps, able to participate in, and benefit from, activities and services supported by Federal funds.

All of this is not to say that application of this analytical framework in every case will be easy. Nonetheless, in spite of the difficulties which may arise in case-by-case applications, the analytical framework focusing on the provision of

medically beneficial treatment to handicapped infants is the correct one under the statute, and is capable of application.

Applicability of Section 504 When Hospital Is Incapable of Providing Treatment

A number of commenters questioned the applicability of section 504 in cases where the hospital, due to lack of sophisticated equipment, medical specialists, or other factors, is incapable of providing the treatment needed by a particular infant. These commenters appeared to suggest that the Department would find such a hospital to be in violation of section 504 because it did not provide the medically beneficial treatment it was u able to provide.

Response

The answer on the applicability of the law in such a case is as clear as the applicability of common sense. Common sense indicates that if a patient needs treatment which a hospital cannot provide, the hospital will try to refer the patient to a facility that can provide it. If the patient is handicapped, the common sense response is the same. The failure of the hospital to itself provide the treatment is not "on the basis of the handicap"; rather, nontreatment is based on the fact that the hospital is incapable of providing the treatment.

Similarly, if the medically indicated course of action for any individual with a condition the facility is incapable of treating is to arrange for that individual to be transferred to a facility where the treatment can be provided, then this transfer cannot be denied to a qualified handicapped person (one who will benefit medically from it) on the basis of the person's handicap.

Responsibilities of Hospitals as Opposed to Physicians

Another challenge to the Department's application of section 504 to health care for handicapped infants was submitted by the Federation of American Hospitals:

> . . .A hospital cannot practice medicine. In fact, many state laws prohibit and punish the unauthorized practice of medicine. Nevertheless, the proposed rules place the responsibility for the physician's decision on the

> hospital. Moreover, assuming that discrimination on the basis of handicap exists, it is *not* discrimination on the part of the hospital, it is the discrimination of the physician and/or parents who are not recipients of federal financial assistance as that term is defined under the Rehabilitation Act. Therefore, insofar as they apply to hospitals, not physicians and parents, the proposed rules are also totally misdirected.

Response

The Department disagrees with the comment's implications that the law in any way requires hospitals to engage in the unauthorized practice of medicine, and that hospitals have no authority to prohibit discrimination by physicians.

It is the Department's view that a hospital has the authority to condition a physician's staff membership or renewal of membership on an agreement to abide by the hospital's policy of nondiscrimination. Indeed, the Department's conditions for hospital participation in the Medicare program require that a hospital have "an effective governing body legally responsible for the conduct of the hospital as an institution." 42 CFR 405.1021. Those conditions also require that a hospital have:

> a medical staff organized under bylaws approved by the governing body, and responsible to the governing body of the hospital for the quality of all medical care provided patients in the hospital and for the ethical and professional practices of its members.

42 CFR 405.1023.

Under those conditions the medical staff is also "responsible for support of . . . hospital policies." 42 CFR 405.1023(a). Standards set forth in the accreditation manual for hospitals, published by the Joint Commission on Accreditation of Hospitals, also recognize the responsibility of the governing body to adopt and approve bylaws consistent with all applicable laws and regulations. The accreditation manual also emphasizes that the governing body has the responsibility for the conduct of the hospital's operation and that the medical staff is responsible to the governing body.

It is the Department's position therefore that a hospital has the right to establish and implement a policy of nondiscrimination among its employees and medical staff, and that this does not constitute an unauthorized practice of medicine by the institution.

Applicability of Section 504 to Adults

Several commenters raised the issue whether section 504 would also be applicable to issues relating to medical care provided to adults. For example, the Department received the following comment from a doctor in San Antonio, Texas:

> As a doctor who practices on adult patients, what I find most worrisome about this whole sorry affair is that the reasoning behind the proposed rules applies at least as well to adults as to infants with congenital defects. Should every patient, no matter how old or ill, be forced to receive the "benefits" of cardiopulmonary resuscitation? Should a ninety-year-old man with a stroke which has caused him to develop pneumonia be subjected to weeks on a respirator in hopes of getting him well enough to go to a nursing home, where the same basic problem is sure to lead to another bout of pneumonia? Should a senile, combative eighty-year-old lady with a breast mass have a biopsy and mastectomy? Certainly a stroke and senility are handicaps if Down's syndrome is.

Response

Although section 504 is, of course, applicable to issues relating to health care provided to adults, the unique issues relating to health care for handicapped infants significantly affect the application of the law and justify the special procedures established by the final rules.

The special needs of infants and minors have long been recognized by most states, as its evidenced by the enactment of child abuse and neglect statutes. These statutes, in most instances, specifically reference the failure to provide necessary medical care to minors as constituting child abuse or neglect, and establish special remedial authorities.

In contrast, most adult patients are viewed by courts as being competent to give or withhold consent regarding medi-

cal treatment for themselves. In the case of adults incapable of making decisions, due to senility, mental retardation, or the like, courts have applied the "substituted judgment" doctrine to try to ascertain the incompetent patient's own wishes through available evidence and by asking what a reasonable person in the patient's situation would do.

The circumstances which give rise to the special procedures established by every state to protect children are the same circumstances which give rise to the special procedures established by the final rules to apply section 504 to matters relating to health care for handicapped infants.

Limitations on Obligations Imposed By Section 504

A number of commenters called attention to judicial decisions indicating limitations on the extent to which section 504 mandates that recipients of Federal financial assistance undertake substantial changes in their programs or activities.

As stated by the American Academy of Pediatrics:

> Case law interpreting section 504 suggests the existence of limitations beyond which the statute cannot reach, giving rise to the question of whether HHS' rule would impose on providers unwarranted affirmative action burdens. In *Southeastern Community College v. Davis*, 442 U.S. 397 (1979), the Supreme Court considered the claims of a licensed practical nurse that her denial of admission to a college nursing program on the basis of her hearing disability violated section 504. The college had determined that Davis' impairment was such that, even with a hearing aid, she would be unable to participate fully in the program and function effectively as a nurse. According to the plaintiff, however, the college should not have taken her handicap into account in determining whether she was "otherwise qualified" for the program, but, rather, should have confined its inquiry to her academic and technical qualifications. The Court rejected this argument, finding that section 504 "by its terms does not compel educational institutions to disregard the disabilities of handicapped individuals...." 442 U.S. at 405.
>
> Davis argued further that HHS regulations implementing section 504 required that the nursing program

be modified to accommodate her, to which the Court replied:

> If these regulations were to require substantial adjustment in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals, they would do more than clarify the meaning of § 504. Instead, they would constitute an unauthorized extension of the obligations imposed by that statute. *Id.* at 410....

Response

The only affirmative step required of recipient hospitals by the final rules is to post an informational notice. As explained in the preamble, the Department has sought to tailor the notice, with respect to both its wording and the locations for its posting, so as to avoid any disruptive or administratively burdensome effects. The posting of notices to advise individuals of protections provided by Federal laws is very common in connection with a wide range of civil rights, health and safety, consumer protection, labor standards, and other Federal laws. The posting of this notice cannot be credibly argued to constitute the kind of excessive regulation prohibited by the *Davis* doctrine.

The other provisions of the final rule which affect hospitals, the clarification regarding access to records and the narrow exception to the ten-day notice rule, similarly impose no appreciable administrative burdens on hospitals. The provision of the final rules relating to state child protective services agencies also, as explained in the preamble, imposes no significant burdens.

The case-by-case application of section 504 and existing regulations, entirely separate from any mandatory provision of the final rules, is, of course, subject to the *Davis* limitations. However, as clearly evidenced by the guidelines set forth in the appendix to the final rules, these limitations have been fully complied with in connection with the Department's interpretations of the application of section 504 and in its enforcement processes.

Section 504, as the *Davis* decision recognized, requires the operation of a recipient's program in a nondiscriminatory fashion. The Department's interpretations and procedures

applicable in this context require no more. The guidelines in the appendix make clear the Department interprets section 504 as not requiring the provision of futile treatments and as respecting reasonable medical judgments. Further, they make clear that investigative procedures have been specially crafted to avoid substantial administrative burdens. The basis of the Supreme Court's decision in *Davis* was that because the Court found it unlikely that the plaintiff could benefit ultimately from the nursing program, the college's refusal to make substantial modifications to its educational program to accommodate the plaintiff was not discriminatory. The appendix guidelines make clear that the Department's interpretation of section 504 in this context carefully adheres to this ability to benefit requirement.

The *Davis* decision did not authorize the evasion of section 504 obligations under the guise that adhering to the nondiscrimination mandate may require some attention. However the courts ultimately refine the doctrine that there are limitations on the scope of section 504, it is the Department's firm position that those limitations are in no way touched by the mandatory requirements of the final rules, nor will they be touched by case-by-case application of the law consistent with the guidelines set forth in the appendix to the final rules.

Medicare and Medicaid as "Federal Financial Assistance"

A number of commenters also disputed the Department's legal authority for the rules on the grounds that participation by hospitals in the Medicare and Medicaid programs did not bring them within the coverage of section 504 on the grounds that Medicare and Medicaid are not "Federal financial assistance" within the meaning of the Act.

Response

The Department's position, consistently held since the Medicare and Medicaid programs were originally enacted in 1965, that Medicare Part A payments to hospitals and Medicaid constitute Federal financial assistance for purposes of applicability of title VI of the Civil Rights Act of 1964 and the nondiscrimination statutes modeled after it, including section 504, is unchanged.

Because the rules do not specifically refer to the Medicare or Medicaid programs, the validity of the rule is not dependent upon the Department's long-standing interpretation. However, hospital officials who believe their hospitals are not subject to these civil rights laws may wish to inform themselves of the Department's position and the substantial legal support for it.

The Department's position has been clear, unequivocal, and consistent. The appendix to the Department's title VI regulations lists Medicare and Medicaid as programs of Federal financial assistance. 45 CFR Part 80, Appendix A, Part 1, No. 121, and Part 2, No. 30. The appendix to HHS's section 504 regulations makes clear HHS's interpretation that the scope of jurisdiction of section 504 is the same as that for title VI. 45 CFR Part 84, Appendix A, Subpart A, No. 2.

The legislative history of the Medicare statute makes clear that Medicare payments to hospitals were intended to constitute Federal financial assistance for purposes of the applicability of title VI of the Civil Rights Act, and thus section 504 as well. Speaking on the floor of the Senate in support of the Medicare bill, Senators Ribicoff and Hart stated unequivocally that title VI was applicable to hospitals participating in Medicare. Senator Ribicoff: "[H]ospitals and other institutions have . . . to abide by Title VI of the Civil Rights Act." 111 Cong. Rec. 15803 (1965). Senator Hart:

> In addition to the new economic independence it will create, I am hopeful that the bill will promote first class citizenship in another fashion also. We decided last year, and wrote into law, that federal tax dollars collected from all the people may not be used to provide benefits to institutions or agencies which discriminate on the grounds of race, color, or national origin. This principle will, of course, apply to hospital and extended care and home health services provided under the social security systems, and *will require institutions and agencies furnishing these services to abide by Title VI of the Civil Rights Act of 1964*. Id. at 15813 [emphasis supplied].

In addition, the legislative history of the Civil Rights Act supports this position. In the most complete analysis of title VI contained in the House Judiciary Committee's Report,

the additional views of seven supporters of the legislation, uncontroverted in any section of the report, specifically made reference to the predecessor program to Medicaid and clearly stated congressional policy underlying title VI:

> In a related fashion, racial discrimination has been found to exist in vendor payment programs for medical care of public assistance recipients. Hospitals, nursing homes, and clinics in all parts of the country participate in these programs and, in some, Negro recipients have received less than equal advantage.
>
> * * * * *
>
> In every essential of life, American citizens are affected by programs of Federal financial assistance. Through these programs, medical care, food, employment, education, and welfare are supplied to those in need. For the government, then, to permit the extension of such assistance to be carried on in a racially discriminatory manner is to violate the precepts of democracy and undermine the foundations of government.

H.R. Rep. No. 914, 88th Cong. 2d Sess. (Additional Views on H.R. 7152 of Hon. William M. McCulloch, et al.).

Courts which have dealt with this issue have found Medicare and Medicaid to constitute Federal financial assistance for purposes of establishing civil rights jurisdiction. A recent such case is *United States* v. *Baylor University Medical Center*, 564 F. Supp. 1495 (N.D. Tex. 1983). Citing HHS regulations indicating that Medicare and Medicaid are Federal financial assistance, case law in which courts "have had little difficulty" in finding that they are Federal financial assistance, the legislative history of the Medicare statute, long-standing agency interpretation, and the broad construction which must be given to remedial civil rights statutes, the court found that Medicare and Medicaid are Federal financial assistance for purposes of section 504 coverage. The court also specifically rejected the medical center's argument that Medicare and Medicaid payments are exempt from the definition of "Federal financial assistance" on the grounds of being under contracts of insurance. The Court distinguished insurance programs, by noting that Medicare is funded by mandatory taxes and Medicaid by general revenues, rather than through a system of risk-based premiums.

Other cases supporting the position that Medicare and Medicaid payments are Federal financial assistance are *NAACP* v. *Wilmington Medical Center*, 657 F.2d 1332 (3d Cir. 1981) (the court noted its jurisdiction was based on the hospital's receipt of Medicare and Medicaid funding); *United States* v. *Cabrini Medical Center*, 497 F. Supp. 95, 96, n.1 (S.D.N.Y. 1980); *Cook* v. *Oschner*. No. 70-1969 (E.D. La., Feb. 12, 1979) (the defendants' argument that Medicare and Medicaid payments did not constitute Federal financial assistance was rejected by the district court during pretrial motions); *Flora* v. *Moore*, 461 F. Supp. 1104, 1115 (N.D. Miss. 1978); and *Bob Jones University* v. *Johnson*, 396 F. Supp. 597 (D.S.C. 1974), *aff'd.*, 529 F.2d 514 (4th Cir. 1975) (court held that VA benefits to students constituted Federal financial assistance to the university and noted their similarity to Medicaid).

The basic congressional policy underlying title VI, section 504 and related statutes is that federally funded programs and services are to be administered in a nondiscriminatory fashion. The Medicare and Medicaid programs were established for the purpose of providing medical service to people who otherwise might not be financially able to obtain them. The argument that somehow these federally assisted medical services were not intended to be within the reach of the nondiscrimination rule is clearly contrary to the basic congressional policy. Underscoring this is the fact that HHS spends billions of dollars annually for health care services to the aged, disabled and poor, and virtually all hospitals participate in these programs. According to data of the Health Care Financing Administration (HCFA), HHS, of approximately 6,930 hospitals, 6,737 participate in medicare and virtually the same number in Medicaid. In fiscal year 1982, total hospital costs in the United States were $136 billion. Of this, $47.9 billion were HCFA expenditures ($36.3 billion, Medicare, $11.6 billion, Medicaid). Approximately 36 percent of all hospital costs in the United States are financed through the Medicare and Medicaid programs. *See HCFA Statistics* (Publication No. 03155, Sept. 1983).

It should also be noted that there are no persuasive arguments for distinguishing Medicaid and Medicare on the ques-

tion of whether they constitute Federal financial assistance to hospitals. Although Federal Medicaid funds flow through the states, the states' relationship to the hospitals in Medicaid is essentially the same as that of the Federal government to the hospitals in Medicare. HHS regulations for both title VI and section 504 specify that recipients of Federal financial assistance include all subrecipients which receive funds from a recipient. 45 CFR 80.13(i), 84.3(f).

In addition, Medicare and Medicaid cannot be considered procurement contracts for purposes of the statutory exemption from civil rights jurisdiction in connection with such contracts. Unlike the relationship that exists under procurement contracts, health care providers promise only that if they serve an eligible beneficiary of the program, they will look to the government for payment of all but specified items. In addition, under Medicare and Medicaid the level of services is determined by providers who are not acting as agents for the government and are not discharging an obligation the government has assumed. Rather they are—with Federal assistance—engaging in activities they have long performed. In this respect Medicare and Medicaid payments are indistinguishable from grants to pay the costs of medical services. Indeed, those payments often cover medical costs of indigent patients that hospitals would otherwise be required to absorb pursuant to their other legal obligations. In contrast, under a procurement contract the government acts on its own account as a consumer of goods, such as typewriters and paper clips, or services, such as hotel accommodations and rental car services for traveling employees. The level of services under procurement contracts is determined by the government and not, as under Medicaid or Medicare, by the provider.

Furthermore, the Medicare and Medicaid programs do not fall within the statutory exemption from the definition of Federal financial assistance for any payments pursuant to "a contract of insurance or guaranty." 42 U.S.C. 2000d-1, 2000d.4 (title VI); 45 CFR 84.3(h) (section 504). The principal object of the Medicare and Medicaid programs is to provide service. Medicare and Medicaid programs cannot properly be characterized as, or analogized to, a contract of

insurance. Benefits under these programs are not measured by any fixed premium paid by the beneficiary to the government; the government reimburses for the reasonable cost incurred by the provider in rendering services. Missing from both reimbursement plans is that essential element of insurance—the assumption of risk. The Medicare and Medicaid programs do not purport to indemnify for nonpayment by the beneficiary. The hospital, in becoming a provider of services under these programs, agrees to look to the government for payment and to accept the reimbursement from the government as full payment, except for the deductible and coinsurance. The beneficiary does not incur any obligation to pay for those services which are covered by the agreement between the provider and the government.

Nor do Medicare and Medicaid constitute contracts of guaranty. Essential to a definition of a contract of guaranty is a primary obligation on the part of the individual for whom the guaranty is given. A contract of guaranty is a promise to pay or an assumption of performance of some duty upon the failure of another who is primarily obligated in the first instance. In contrast, the reimbursement provisions of the Medicare and Medicaid programs are not activated by the failure of the individual recipient to pay for the medical services covered by agreement between the government and the hospital.

It is the absence of these elements which distinguishes Medicare and Medicaid from programs that Congress intended to be excluded under the contract of insurance or guaranty exception, such as mortgage guarantees under FHA or VA and depositors' insurance under FDIC, where the role of the government is clearly as an insurer or guarantor and Federal monies are involved only if the private party does not meet his or her obligation. It is also noteworthy that the American Hospital Association apparently concluded in 1966, when Medicare was instituted, that hospitals receiving Medicare were recipients of Federal financial assistance for title VI purposes. The AHA solicited and printed in its journal a question and answer article prepared by the former Department of Health, Education and Welfare to help hospitals understand what they were required to do

to comply with title VI to receive Medicare funds. *See* "Hospitals and Title VI of the Civil Rights Act of 1964, Questions and Answers," *Hospitals*, June 1, 1966. Also, pursuant to 45 CFR 84.5, hospitals which participate in the Medicare and Medicaid programs have submitted assurances to HHS that they would comply with section 504 and the applicable regulations.

Accordingly, as demonstrated by this brief summary of points in support of the Department's long-standing position, hospitals which participate in the Medicare and Medicaid programs are recipients of Federal financial assistance for the purpose of establishing section 504 jurisdiction.

"Program or Activity" Receiving Federal Financial Assistance

Another argument presented by some commenters to dispute the legal authority for the proposed rule is that even if Medicare and Medicaid are "Federal financial assistance," they are not "a program or activity" which provides medical care to handicapped infants. The argument appears to be that, purportedly following the analysis of the government's brief to the Supreme Court in the pending case of *Grove City College* v. *Bell*, 687 F.2d 684 (3d Cir. 1982), *cert. granted*, 51 USLW 3611, February 22, 1983 (#82-792), the "program or activity" which receives Federal financial assistance in the form of Medicare and Medicaid payments to a hospital is the fiscal accounting office of the hospital.

As stated by the American Academy of Pediatrics:

> ...to the extent, then, that the government believes that Title IX cannot extend beyond the financial aid office, is difficult to understand how section 504 could extend to nurseries, maternity wards, and neonatal intensive care units simply because the medical expenses of primarily elderly Medicare beneficiaries are reimbursed in the accounting office.

Response

The Department believes this argument is without merit. The position advanced by the government in *Grove City* is that in determining what constitutes the Federally assisted program, it is necessary to examine both the nature of the

Federal program and the organizational practices of the recipient institutions. *Grove City* involves the Basic Education Opportunity Grants program (BEOG), in which grants are made to students and used by the students to pay for tuition, fees, room and board. The recipient institutions operate financial aid programs under the direction of a financial aid office, with a separate budget and a specific purpose, to provide financial aid to students who otherwise could not afford to attend the college. BEOG's are one component of the college's financial aid program. In view of the nature of the Federal BEOG program and the organizational practices of colleges, it is the college's financial aid program that receives the Federal assistance. Although, conceivably, an effort could be undertaken to "trace" the "ripple effects" of the BEOG money throughout the college, the government's position in *Grove City* is that this is not what Congress intended in enacting the program specificity requirement in the applicable civil right statutes.

The circumstances involved in connection with Medicare and Medicaid reimbursements to hospitals are entirely different from those involved in BEOG's and colleges. Rather than providing assistance to a general financial aid program operated by the recipient, Medicare and Medicaid payments to hospitals are primarily for particular medical services provided to particular patients who received services in particular units of the hospital. It is services provided to particular beneficiaries by the hospital's operating room, x-ray department, laboratory, pediatrics ward, or other organizational units that give rise to the Federal reimbursements. In addition, the hospital's organizational and accounting practices provide for Federal reimbursement for a proportionate share of administrative costs, housekeeping, depreciation of physical plant, and other general expenses, all specifically itemized and specifically eligible for reimbursement.

Also unlike colleges, "tracing" Medicare and Medicaid reimbursements within hospitals is not dependent upon looking for "ripple effects" of the Federal funds. Rather, it is the specific identification of actual services and costs which gives rise to reimbursements based specifically thereon.

Therefore, the Federally assisted program of a hospital is not, as a commenter suggested, the accounting office of the hospital, any more than the Federally assisted program of a college is the accounting office or comptroller. An examination of the applicable Federal programs and the recipient's organizational practices makes clear that the issues presented in the *Grove City* case, and the positions taken by the government in that case, do not undermine the legal basis for the final rules or the application of section 504 to health care for handicapped infants.

It should also be noted that whatever subtleties or twists are ultimately associated with the interpretation of "program or activity," the final rules specifically accommodate the program specificity requirement pertaining to the posting of the informational notice as applicable to each recipient that provides health care services to infants "in programs or activities receiving Federal financial assistance." If, on the basis of the Supreme Court's eventual decision in *Grove City* or other factors, limitations evolve on what programs or activities of hospitals are covered by section 504, those limitations will be accommodated by the text of the rules.

Services vs. Employment as Jurisdictional Limitation

The Federation of American Hospitals advanced another argument in behalf of the proposition that the Department has no legal authority to issue the final rules. The Federation commented:

> The Rehabilitation Act of 1973 (Pub. L. 93-112) does *not* apply to hospitals. Federal circuit courts of appeal which squarely address the issue uniformly hold that the Act does *not* apply to hospitals as recipients of Medicaid or Medicare funds. These courts have held that the Rehabilitation Act applies to recipients of federal financial assistance if, and only if, that assistance has the primary objective of providing employment.
>
> In *United States* v. *Cabrini*, 639 F.2d 908 (2d Cir. 1981), the Court . . . [held] that the Office for Civil Rights was not authorized to investigate a complaint by a hospital employee that he was discharged for mental disability.... *Tragesar* v. *Libbie Rehabilitation Center*,

Inc., 590 F.2d 87, 89 (4th Cir. 1978), *cert. den'd*, 442 U.S. 947; *Scanlon* v. *Atascadero State Hospital*, 677 F.2d 1271, 1272 (9th Cir. 1981); see, also, *Carmi* v. *Metropolitan St. Louis Sewer District*, 620 F.2d 672, 674-675 (8th Cir. 1980), *cert. den'd*, 101 S. Ct. 249 (1980)...

As there is no legal authority supporting the proposition that the Rehabilitation Act of 1973 applies to hospitals receiving Medicare and Medicaid funds since the primary objective of those programs is *not* employment; the proposed rules must be withdrawn.

Response

The Federation's legal argument is incorrect. The *Tragesar/Carmi/Cabrini/Scanlon* line of cases holds that section 504 does not provide jurisdiction *over employment practices of recipients* unless the Federal financial assistance has the primary objective of providing employment. These cases held that section 505(a)(2) of the Rehabilitation Act, making the "remedies, procedures, and rights set forth in title VI of the Civil rights Act of 1964" applicable to section 504, incorporated the restriction in section 604 of the Civil Rights Act of 1964, which makes title VI inapplicable to employment practices unless the Federal financial assistance has the primary objective of providing employment. Two circuit courts have recently held that the reference to title VI procedures in section 505 did not intend to incorporate the employment restriction. *Jones* v. *Metropolitan Atlanta Rapid Transit Authority*, 681 F.2d 1376 (11th Cir. 1982), *petition for cert. pending*, No. 82-1159 (filed January 11, 1983); *LeStrange* v. *Consolidated Rail Corporation*, 687 F.2d 767 (3d Cir. 1982), *cert. granted*. The Supreme Court is expected to decide this issue during its present term.

Regardless of the merits of that issue, it has no relevance to the final rules. No case has held, as none could based on the clear statutory language and congressional intent of section 504, that section 504 applies only to a very narrow segment of employment practices, and has no applicability to the provision of services and benefits under programs and activities receiving Federal financial assistance.

B. ENFORCEMENT PROCESSES

A prior section of this preamble discusses investigative procedures of the Department applicable in the context of health care for handicapped infants and an analysis of related comments. This section discusses other comments pertinent to this issue.

Sanction for Non-Compliance

A number of commenters stated objections to the sanction for non-compliance, termination of Federal financial assistance. The basic thrust of these comments was that termination of all or a portion of a hospital's Federal financial assistance would be unfair in the context of difficult treatment decisions, later judged by HHS to be in non-compliance with section 504. As stated by the American Hospital Association:

> The penalty for even inadvertent violation would be severe. The Department asserts authority and threatens to terminate all federal financial assistance that the individual or institution may be receiving. Moreover, the threat of such penalties may encourage physicians and others to refuse to participate in programs funded by the Federal government, particularly those supporting specialized treatment facilities for the newborn. In cases where the institution depends for operation on significant federal funds unrelated to handicaps, this policy may, for example, cause the closing of neonatal units to avoid the risk of losing federal funds. Such a result could reduce access to needed care for many infants who could be helped with safe, timely and effective treatment.

Response

It is correct that under the law, noncompliance with section 504 can result in termination of Federal financial assistance to the particular program or activity, or part thereof, in which the noncompliance has been found. However, the existing procedural and legal requirements applicable to any action to terminate Federal financial assistance are more than adequate to protect against an unfair result.

The Rehabilitation Act provides, in section 505(a)(2), that the remedies, procedures and rights set forth in title VI of

the Civil Rights Act of 1964 shall be applicable to actions to enforce section 504. These title VI procedures provide substantial due process protections.

First, before Federal financial assistance can be terminated, the recipient must have an opportunity for a hearing before a court or administrative law judge, who must expressly find that there has been a failure to comply with the law or applicable regulations.

Second, before Federal financial assistance can be terminated, there must be a finding that compliance cannot be secured by voluntary means. Therefore, a recipient that has been found to have violated section 504 in connection with the health care provided to a handicapped infant will not lose its Federal funding unless it refuses to adopt the standards or procedures necessary to prevent future noncompliance.

Third, in any case, the burden of proof that there has been noncompliance and that it cannot be corrected by voluntary means is on the government. The standards for this determination are those set forth in the appendix to the final rules which includes the guideline regarding deference to reasonable medical judgments.

Fourth, the Department's regulations provide for appeal of adverse administrative law judge decisions to the Department's Civil Rights Reviewing Authority, which is independent from the Office for Civil Rights. Recipients may then seek review by the Secretary of the decisions of the Reviewing Authority. Further, the Department's final decision is subject to judicial review.

Therefore, there is no basis for an assertion that Federal financial assistance can be precipitously terminated on the basis of some subjective determinations by a handful of bureaucrats. In fact, due primarily to the statutory requirement that recipients be given full opportunity to voluntarily comply, the chance, based on all prior governmental experience under title VI and the statutes modeled after it, that any recipient will actually lose its Federal financial assistance is rather remote.

OCR Investigations at Strong Memorial Hospital and Vanderbilt University Hospital

In support of criticisms of OCR investigations, a number of commenters cited reports of hospitals which were subjects

of OCR investigations at the time the interim final rule was put into effect in March. As stated by the American Hospital Association:

> The mischief of the federal hotline enforcement mechanism was illustrated graphically during the short life of the March rule by the occurrences at Vanderbilt University Hospital in Nashville and Strong Memorial Hospital in Rochester, NY. In the Vanderbilt case, an anonymous hotline caller alleged that ten named children at the hospital were not being fed or given proper medical care. A federal "Baby Doe squad" (consisting of lay officials from the regional and national staffs of the Office of Civil Rights and a hired neonatologist) arrived at the hospital that evening and met with the attending physicians for each of the children, the chief of pediatrics, the chief pediatric resident, and the associate director for nursing, after which the neonatologist examined each child. On the following day, the investigative team examined medical records and interviewed nursing staff, hospital administrators, and the chief of pediatrics.
>
> [The investigation] resulted in the delayed discharge of one patient, delayed the transporting of children to scheduled surgery, necessitated the re-ordering of laboratory reports, diverted nurses from patient assignments, delayed nursing shift reports, and consumed, in total, substantial amounts of professional time that otherwise would have been devoted to the care of patients, including the infants who were the subjects of the investigation.
>
> The Strong Memorial experience was strikingly similar and even more disturbing. An unidentified hotline caller, whose only information concerning the case apparently came from a newspaper report, triggered an investigation regarding the treatment of conjoined twins in that facility. An identically constituted investigative squad arrived at the hospital, though without any statement of investigative authority or written requests for hospital records. The hospital complied nonetheless with the investigators' requests, only to have the team disagree as to which of them was entitled to the information. The neonatologist member of the team subsequently departed upon learning that the in-

vestigators had failed to obtain the parents' consent to examine the infants.

The effects of the investigation in this case went well beyond the diversion of patient care resources and delays in treatment. The parents of the conjoined infants were subjected to substantial undesired publicity. Parents of other critically-ill children were led by this publicity and the lack of clarification from federal investigators to become apprehensive about the adequacy of care provided at Strong Memorial. Before the investigation concluded, one family removed its seriously-ill child from the facility prior to the completion of treatment, on the belief that the hospital was intentionally harming children.

Response

The Department strongly disputes the accounts of these investigations provided by personnel affiliated with the two hospitals. The reports referenced by commenters appear to be based upon affidavits prepared in connection with litigation initiated by the American Hospital Association challenging the implementation of the March interim final rule. Contrary to these reports, both of these investigations were conducted very expeditiously and professionally, and every effort was made to minimize any disruption to the hospitals. In addition, during the course of these investigations (and prior to their being raised in the litigation), officials of neither hospital complained to OCR regarding the conduct of the investigations, nor, in either case, did hospital personnel complain to OCR personnel that the investigations were causing significant disruptions to the patient care activities of the hospital.

With respect to the Strong Memorial Hospital case, the following are the pertinent facts of the investigation:

a. On the morning of March 29, 1983 (seven days after the effective date of the interim final rule), a complaint was received on the hotline about conjoined infants recently born at Strong Memorial Hospital in Rochester, New York.

b. An investigative team consisting of one investigator from the Washington Office and two from the New York Regional Office was sent to the site to investigate. The team

arrived at approximately 4:30 p.m. Arrangements were made to have a medical consultant also travel to the site.

c. The team met with a hospital administrative officer and the attending physician. The attending physician reviewed the infants' condition and status. He mentioned that there was a no-resuscitation order in effect for the twins, should cardiac arrest occur.

d. The attending physician told OCR that the parents were concerned about publicity. OCR assured him that OCR would not discuss the case with the media or otherwise publicize OCR's investigation.

e. The OCR team made no request to interview other staff at that time. The administrator produced a copy of the medical records. The Washington Office investigator received it and said it would not be necessary to produce another copy for the Regional Office. Throughout the investigation, the administrator and attending physician were cooperative and helpful. The attending physician asked the team leader to tell the OCR medical consultant that he could be called late and would be glad to come to the hospital and meet with him, show him the medical records, and let him view the infant. The administrator asked to be called when the medical consultant arrived. The OCR team left the hospital at about 7:30 p.m.

f. The OCR medical consultant arrived in Rochester about 9:15 p.m. and met with the investigative team. Apparently based on a misimpression of his role, the consultant stated he would not review the records or go to the hospital to meet with the physician or view the infants unless the parents consented.

g. On the morning of March 30, 1983, the OCR team and the OCR medical consultant had a telephone conversation with the administrator. He said that he wished the OCR team would not return to the hospital because that investigation was receiving publicity. The team leader decided there was no need to return to the hospital.

h. In summary, the investigative team was on site only three hours in the late afternoon and early evening of March 29.

With respect to Vanderbilt University Hospital, following are the pertinent facts of the case:

a. OCR received a hotline telephone call at 11:45 a.m. on March 23, 1983 (the day after the effective date of the interim final rule), alleging that ten infants at Vanderbilt University Hospital were not receiving treatment and/or nourishment.

b. From 9:30 p.m. to 11:45 p.m. on March 23, 1983, the OCR investigative team, consisting of two investigators from the Atlanta Regional Office, one from the Washington Office, and the OCR medical consultant, met with various members of the hospital staff to discuss the current status of the ten infants.

c. After this meeting, from midnight until 12:30 a.m., the OCR medical consultant physically viewed the infants on the regularly scheduled "rounds" in the company of the Chief Pediatric Resident and the Chief of Pediatrics.

d. From 8:00 a.m. until 2:45 p.m. on March 24, 1983, the OCR investigators and medical consultant reviewed the available medical records of the ten children. Medical records were given to OCR in groups of four and retrieved as needed by the Associate Director of Nursing and other members of the Vanderbilt staff. The Associate Director of Nursing and the hospital staff members were very cooperative, and at no time did they indicate to the investigative team that the review of records was causing any problem. In only one instance did they indicate they needed a chart, and OCR immediately relinquished it. That chart was not subsequently made available for review that day, but a copy of it was mailed to OCR.

e. All records were reviewed with the understanding that if they were needed for patient care they would be retrieved. Computer printouts detailing the admitting diagnosis, age, physician assigned to the case, service area, and the date of admission or transfer for all ten children were given to the OCR team. The Associate Director of Nursing stated that this printout was readily available because the information was kept on-line for billing purposes and this would not interfere with patient care. The bedside charts were copied

and given to OCR at the end of day because they were needed for patient care.

f. Following the OCR review of the medical records, from approximately 2:45 p.m. to 4:00 p.m. on March 24, 1983, the OCR team interviewed the available nurses who were involved in the primary care of the infants. Five nurses were interviewed for approximately 10 to 15 minutes each. The selection of the nurses was left to the discretion of the Associate Director of Nursing; she scheduled them so that patient care would not be disrupted.

g. At no time did the Chief of Pediatrics or Associate Director of Nursing indicate that the OCR investigation was placing patients in jeopardy.

h. The hospital staff asked the OCR team for a preliminary statement of findings. The team leader responded that OCR investigators are not authorized to make findings during an investigation. An investigative report would have to be prepared following the investigation, and this would have to be reviewed before the agency could issue findings.

i. The total time spent on-site to investigate the circumstances relating to all ten infants was approximately eleven hours. The total time occupied of the two Vanderbilt doctors directly involved was seven and one-half hours. Every effort was made to minimize any disruption, and at no time during the investigation did hospital personnel complain to OCR that the investigation was disrupting patient care.

Therefore, contrary to the reports of hospital officials, prepared to support litigation against the Department, these investigations were conducted professionally and every effort was made to minimize any disruptions.

Concerning the report that, according to a hospital official, one family withdrew a seriously ill patient from the Strong Memorial Hospital before completion of treatment due to fears that the hospital was intentionally harming children, caused by their reading of local newspaper accounts of the investigation, the report provided no further details, and the department has no basis to confirm the event or the motivations for it. However, the firm policy of not commenting to the media regarding an open investigation was adhered to strictly in the Strong Memorial Hospital case. Media atten-

tion was not provoked by OCR, nor did OCR make any statement to the media which could have implied any belief by OCR that the allegations of the complaint were substantiated.

Danger of Overtreatment

Several Commenters expressed the concern that the existence of OCR's enforcement process would cause hospitals and health care professionals to "overtreat"an infant. An example of this is a case in which the attending physician or physicians have concluded on the basis of reasonable medical judgment that treatment would be futile, but, due to a fear that an OCR investigation might come to a contrary conclusion, nevertheless provide futile treatment, which, while prolonging the process of dying, causes suffering to the infant and severe distress to the infant's parents. In connection with adverse ramifications of overtreatment, attention was called to the experiences of one family, as presented in a recent book, *The Long Dying of Baby Andrew* (Little, Brown and Co., Boston, 1983).

Response

The Department believes that whatever the dangers are that physician misjudgments will lead to "overtreatment" of infants, those dangers are not increased by the existence of section 504 or the determination of the Department to see that it is effectively enforced. As indicated above, section 504 does not require that futile treatments, which will do no more than prolong the act of dying, be provided. Moreover, OCR decisions concerning compliance or noncompliance with section 504, informed by the expert evaluation of qualified medical consultants, do not interfere with reasonable medical judgments. Also, in any case, reviewing whether certain care was medically indicated and denied on the basis of the infant's handicap, there are extensive due process protections to assure accuracy of fact finding. Furthermore, even where there is an ultimate finding, after exhaustion of all due process rights, of noncompliance of section 504, no sanction can be implemented unless the recipient hospital refuses to adopt procedures to bring it into compliance.

The Department agrees that in a "close case" it may be prudent to preserve the status quo pending additional consideration regarding whether certain possible treatments are medically indicated, whether that additional consideration is by specialists at the hospital, by medical professionals at a more specialized facility, by some internal hospital review board, or by some state or federal agency. In such a case, the usual practice in most hospitals likely would be to continue life-sustaining care until the appropriate analysis has been secured.

C. ALTERNATIVE APPROACHES

In addition to proposals discussed in the preamble concerning establishment of Infant Care Review Committees, the Department received other suggested alternative approaches.

AMA Proposal: Further Study Prior to Action

The American Medical Association proposed that, rather than adopting any regulation, the Department should initiate a study to include: compilation of data on the incidences of each type of severe impairment in newborns and of successful treatment, unsuccessful treatment and nontreatment in each category; identification of the issues involved in medical management and of mechanisms currently used by hospitals and states; determination of the availability of facilities, financial resources, and public and private social services; and an assessment of the impact of the various alternative means of responding to situations involving severely impaired newborns, including such factors as the ongoing treatment of newborns, the families of severely impaired newborns, the operation of health care facilities, the confidentiality of patient-physician relationship, the malpractice and disciplinary risks of health care providers, the availability of facilities and resources, and the costs of care.

Response

The AMA's proposal for an elaborate study prior to taking any action concerning this matter is not acceptable to the Department. The Department does not believe it is necessary—or in some respects, even possible—to generate

definitive data, information or conclusions on many of the issues identified in the AMA's study proposal.

Much of the data the AMA proposes be compiled concerning the incidence rates of every classification and degree of serious impairment, of respective modes of treatment, of rates of success, nonsuccess and nontreatment, and of issues, mechanisms, resources and costs is probably impossible to compile. These matters are the subject of an entire discipline of medical practice and study. To suggest that a government study will somehow generate conclusive information on these issues appears naive at best.

The call for a study of the resources available and the costs of care for newborns appears aimed at identifying an aggregate cost to society of putting into practice the principle of providing all handicapped infants with medically beneficial treatment. Because there are no reliable data available on the extent to which handicapped infants are now denied medically beneficial treatment, it would appear impossible to develop even reasonable guesses regarding aggregate costs. Of course, in the overall context of all health care expenditures in the United States, the costs are certain to be relatively small.

In question 6 included in the preamble to the July 5 proposed rule the Department sought input on this cost issue by asking for "examples of cases where medically indicated treatment would, but for the legal requirements of section 504, be withheld." No information was submitted to the Department in response to this question which provides a basis for meaningful cost projections. Although the AMA did not address the issue, other major medical organizations who commented on the cost issue indicated that cost should not be a determinative factor in deciding upon treatment for seriously impaired newborns.

The Department agrees there is utility in assessing the impact of various alternative means of addressing and responding to situations involving severely impaired newborns. Much of this preamble focuses on precisely this issue. Although the AMA did not identify the "various alternative means" it believes to exist to deal with this issue, based on the comments received by the Department, there would ap-

pear to be three major approaches: (1) Enforcement of section 504 (hereinafter "the section 504 approach"); (2) review by hospital review boards, such as Infant Care Review Committees (hereinafter "ICRC approach"); and (3) the traditional doctor-parent approach.

Concerning impact on treatment of newborns, the section 504 approach is most directly focused on the provision of medically beneficial treatment. The ICRC approach would be organized to have this as its objective, but lacks a mechanism to assure this as a relatively uniform result among thousands of hospitals. The connection between actual practice and this objective appears most potentially attenuated under the traditional doctor-parent approach, under which there are many thousands of individual decisionmaking units.

With respect to the impact on families to the extent some parents would not consent to medically beneficial treatment, the traditional doctor-parent approach would appear least likely, given the lack of a mechanism to facilitate uniformity, to resort to the system provided by State law to review the propriety of parental decisions. The ICRC approach appears more likely, and the section 504 approach most likely, to produce this result in that they incorporate standards that the lack of parental consent for medically beneficial treatment must be brought to the attention of the appropriate state agencies.

Concerning the impact on the operation of health care facilities, the traditional doctor-parent approach would appear to have the least impact because the facilities have no formalized involvement in the decisionmaking process. Both the section 504 approach and the ICRC approach would likely result in greater involvement of the health care facility.

With respect to the confidentiality of patient-physician relationships, the traditional physician-parent approach is most protective of confidentiality in that it does not provide for the sharing of information with others. Both the section 504 approach and ICRC approach involve the sharing of information with others, but both incorporate adequate confidentiality safeguards.

With respect to the impact on malpractice and disciplinary risks (assuming that by disciplinary risks, the AMA is referring to revocation of medical licenses, or the like) of health care providers, to the extent physicians have malpractice or disciplinary vulnerabilities relating to incorrect diagnoses or inadequate knowledge of prevailing medical judgments regarding indicated treatments, approaches would facilitate the avoidance of failure to provide medically indicated treatment would appear to reduce those vulnerabilities. Because none of the approaches involve doctors or hospitals overruling parental decisions, and because reports to State agencies of suspected instances of neglect of children are immunized by state law from legal vulnerability, none appear to increase malpractice or disciplinary risks in the context of actions which would be taken when parents refuse consent for medically beneficial treatment.

With respect to the impact on costs, available resources, and available facilities, to the extent the different approaches affect the likelihood that handicapped infants will receive medically indicated treatment, these factors will be correspondingly affected. However, the Department is unaware of any data base for quantifying these factors.

In summary, the Department believes adequate information is on the record to provide a basis for prudent and informed decisions on this issue. Regarding several of the issues raised by the AMA proposal, the Department agrees there would be advantages in having more detailed information and data. However, obtaining more definitive information on some of these issues is impracticable or impossible due to the lack of reliable data base and a viable methodology to obtain better data. Therefore, the Department believes there would be very little to be gained from another government study of this issue.

D. FACTUAL BASIS FOR FINAL RULES

NPRM Explanation

A number of commenters challenged the Department's factual basis for the proposed rule, as set forth in the July 5 notice of proposed rulemaking. The points argued in support

of the position that the factual basis did not provide a sufficient foundation for the regulation were:

(a) Judge Gesell questioned the factual basis for the March 7 rule.

(b) The 1973 article by Drs. Duff and Campbell of the Yale-New Haven Hospital documenting that of 299 consecutive deaths occurring in that special care nursery, 45 (14%) were related to withholding treatment, cited in the preamble to the proposed rule, was too old to be reliable.

(c) The several specific cases cited in the preamble had various probativity defects.

(d) The 1977 article reporting the results of a survey of pediatricians suggesting discriminatory attitudes was outdated, not statistically valid, and otherwise lacked current probative value.

(e) The findings of the report of the President's Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research entitled *Deciding to Forego Life-Sustaining Treatment* contradict the Department's factual basis.

(f) Because "discrimination against the handicapped in the delivery of health care services does not only involve handicapped newborns," there is "no compelling rationale for a set of rules targeted solely at this population."

Response

The Department continues to believe that a substantial factual basis exists for the proposed rule. First, it should be noted that Judge Gesell, although he found many relevant factors to have been inadequately considered in connection with issuance of the March 7 rule, did not find the factual basis inadequate to support "undertaking a regulatory approach to the problem of how newborns should be treated in government-financed hospitals."

Second, the arguments that the well-documented Duff and Campbell study is outdated are based on the personal opinions of several commenters. These personal opinions, although in some cases those of highly respected medical professionals, were not backed up by any empirical data even

remotely resembling the very detailed evidence of the Duff and Campbell study.

Third, the conclusion of the President's Commission that decision making about seriously ill newborns "usually adheres" to proper standards cannot be fairly represented as evidence that handicapped newborns should be exempt from basic protections of the law prohibiting discrimination on the basis of the handicap.

Fourth, regardless of the caveats concerning the age of particular cases or the lack of a conclusive finding of illegal discrimination, the several specific cases cited in the preamble to the proposed rule support the proposition that handicapped infants may be subjected to unlawful discrimination.

Fifth, in the absence of any empirical studies or data to bolster their personal opinions, the commenters who suggested that the results, published in 1977, of the survey of pediatricians' attitudes are outdated are not convincing. The article, "Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons," 60 *Pediatrics* 588, reported the results of a survey of 400 members of the Surgical Section of the American Academy of Pediatrics and an additional 308 chairpersons of teaching departments of pediatrics and chiefs of divisions of neonatology and genetics in departments of pediatrics. Responses were received from 267 of the former group (66.8%) and 190 of the latter (61.7%). Responses were anonymous. Among the results of the survey were:

—76.8% of the pediatric surgeons and 49.5% of the pediatricians said they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down's syndrome."

—23.6% of pediatric surgeons and 13.2% of pediatricians would *encourage* parents to refuse consent for treatment of a newborn with intestinal atresia and Down's syndrome. Only 3.4% of pediatric surgeons and 15.8% of pediatricians would get a court order directing surgery if the parents refused.

—63.3% of the pediatric surgeons and 42.6% of the pediatricians said in cases of infants with duodenal atresia and Down's syndrome, where they "accept

parental withholding of lifesaving surgery," they would also "stop all supportive treatment including intravenous fluids and nasal gastric suction."

—62% of all respondents who believe that children with Down's syndrome "are capable of being useful and bringing love and happiness into the home" would nevertheless acquiesce in parents' decisions not to allow surgery for the atresia. Only 7% who so believe indicate that they would go to court to require surgery.

Sixth, there is no requirement in law or policy for the government to prove the magnitude of illegality before establishing basic mechanisms to allow for effective enforcement of a clearly applicable statute.

Evidence of Problems Submitted by Commenters

Additional evidence of the risk that handicapped infants may be subjected to discrimination was submitted by commenters. For example, the Spina Bifida Association of America stated:

> Unfortunately, the SBAA has direct experience of cases in which this principle [of nondiscrimination] has not been followed—instances in which children with spina bifida have been initially denied appropriate treatment. Pediatric neurosurgeon Dr. David McClone of Chicago Children's Memorial Hospital, a member of SBAA's Professional Advisory Committee, has found that 5% of the children with spina bifida referred to him have been victims of treatment denial. Most of these cases, he believes, resulted from ignorance of current therapies and their impressive outcomes.

The Department received a number of comments from practicing nurses regarding the problem and need for the proposed rule. For example, from a Lexington, Kentucky, nurse:

> I am a registered nurse and have worked in the labor and delivery area, newborn nursery and intensive care nursery.... I think the average American would be shocked at the decisions that are made regarding "non-perfect" infants. I have personally heard physicians and nurses talk to new parents about their child and persuade the parents to "let the child die and therefore end

its suffering"—which really meant "let us starve your child to death"—that is certainly not a humane way to "let a child die."

A nurse in Boca Raton, Florida, wrote:

> I am an RN with a specialty in maternal-child health. In the past few years I have had to witness the deaths of innocent children in hospitals where a decision was made not to continue with medical care and assistance.

Another nurse wrote:

> As a nurse (RN) in a neonatal ICU, I feel compelled to write and voice my support of the "Baby Doe rule" now proposed.... Many doctors and nurses openly support withholding or withdrawing medical care.... Due to the ethics of the medical director of the unit, this has only been done once or twice to my knowledge. I would report any cases of neglect I knew of if this number and service were available.... An outside third party is needed to police the cases. Please allow some method of reporting and investigating these babies' cases to be available.

From a nurse in San Diego, California, came the following comment:

> [A]s a practicing registered nurse myself, I believe such regulations permit nurses and staff to act in a patient's best interest—life itself!—without fear of harassment and possible job loss.

In addition, some commenters who opposed the proposed rule appeared to acknowledge that there is a risk that handicapped infants will not receive medically beneficial treatment. For example, the American Society of Law and Medicine, a national, nonprofit professional association, stated:

> There can be no question that some decisions to end life-sustaining care for newborns have been made inappropriately, even if the frequency of this problem has not been established.

Another example of this is the comment by the chairman of the division of pediatrics of a hospital in Illinois:

> We are acutely aware that handicapped individuals (*not* most handicapped newborns) are systematically discriminated against in our society. We are also acutely aware that we, like virtually all members of our

> society, are guilty of having prejudicial beliefs and attitudes about the handicapped. That pediatricians and other health care providers have acted on these negative beliefs and attitudes should come as no surprise. That parents, at least in the initial phase of their relationship with a handicapped newborn, should wish to be spared what is perceived as a burden or even wish that the infant had never been born should come as no shock.
>
> * * * * *
>
> We wholeheartedly agree that in the past these obviously critically important decisions have not been accorded the degree of reflection and care they are due. Given the wide range of possible technological interventions now possible; given the changing conception of the appropriate role of physician and parents in such decisions; and given the need for public accountability for such decisions—we support the idea that the manner in which such decisions have been made in the past needs critical reexamination.

Another example is the comment of the American Academy of Pediatrics:

> The traditional method of a single physician making such judgment [regarding treatment], without exposure to other persons having additional facts, experience, and points of view, may lead to decisions, which, in retrospect, cannot be justified.

Response

The Department believes these comments provide additional support for the Department's conclusions that available evidence indicates there are cases in which handicapped infants are at risk of having life-sustaining, nourishment or medically beneficial treatment withheld solely on the basis of their present or anticipated physical or mental impairments, and that this evidence constitutes a substantial foundation for the establishment of basic procedural mechanisms to facilitate enforcement of section 504.

OCR Investigations to Date

Another argument made by a number of commenters to support criticisms of the adequacy of the factual basis for the

proposed rule was that the experience of the Office for Civil Rights to date in connection with section 504 enforcement activities relating to health care for handicapped infants indicate there is no significant evidence of a problem that the rule could reasonably be designed to deal with. As stated by the American Hospital Association:

> The total absence of verifiable violations, notwithstanding hundreds of hotline calls, also compels the conclusion that either this mechanism is not an effective means to meet any alleged need or, as we believe to be the case, the violations that have been described are not occurring. In either case, a federal regulation is unnecessary.

Response

Rather than support the argument that there is no need for section 504 applicability or enforcement in connection with health care for handicapped infants, the OCR experience to date provides additional evidence that the assumption that handicapped infants will receive medically beneficial treatment is not always justified.

First, it must be noted that the vast majority of the several hundred calls made to the Department were not for the purpose of reporting suspected violations of section 504. Rather, the vast majority of calls were for administrative purposes, such as hospital officials asking questions about the provisions of the March interim final rule, individuals acting on their apparent curiosity to see if anyone would answer the telephone, and other peripheral matters. It should also be noted that the Department's experience under the interim final rule does not provide an adequate basis to make conclusive judgments in any direction because the rule was only in effect for about three weeks, from March 22 until April 14, the day Judge Gesell declared it invalid.

Following is a summary of the Infant Doe cases handled to date, and current as of December 1, 1983.

1. *Bloomington, Indiana.* Investigation into April 1982, death of infant with Down's syndrome and esophageal atresia from whom surgery was withheld on the instructions of the parents. An investigation, delayed due to difficulties in obtaining information sealed by court order, has been conducted. Final administrative action has not yet been taken.

2. *Robinson, Illinois.* May 14, 1982, complaint that hospital (at the parents' request) failed to perform necessary surgery on an infant born with myelomeningocele. Prompt on-site investigation was conducted, involving OCR, the Justice Department and the state child protective services agency. The parents refused consent for surgery; the hospital referred the matter to state authorities, who accepted custody of the infant and arranged for surgery and adoption. The care provided to the infant while these actions were taken was in compliance with section 504. Finding: no violation.

3. *Madison, Wisconsin.* May 7, 1982, complaint that two infant survivors of abortions may have been denied treatment. On-site investigation revealed that two infants, of 26 and 22 weeks gestation, were born alive following abortions; life-saving procedures were applied; neither infant could survive due to extreme prematurity. Finding: no violation.

4. *Kettering, Ohio.* July 26, 1982, complaint that an infant with spina bifida and hydrocephalus was not being treated. Immediate on-site investigation revealed that surgery to correct the spina bifida condition was not performed immediately because the infant had medical complications. Surgery was performed after the infant's condition stabilized. The hospital provided all proper treatment. Finding: no violation.

5. *Barrington, Illinois.* September 17, 1982, complaint that a multi-handicapped infant was not receiving needed treatment. Immediate on-site investigation determined that given the nature and severity of the problems, there were no procedures or services which could have been provided which might have changed or otherwise influenced the outcome for this infant, who died four days after birth. Finding: no violation.

6. *New Haven, Connecticut.* October 12, 1982, complaint (referred from the Department of Justice) that hospital engaged in a pattern and practice of denying medical treatment to handicapped infants. The complaint was included in a compliance review, already in progress. The investigation has been expanded to include several cases involving other Connecticut hospitals. The investigation, which has included review of hundreds of medical files, has not been completed.

7. *Tulsa, Oklahoma.* December 7, 1982, complaint that a baby was being deliberately dehydrated. Immediate on-site investigation determined that the infant had hydranencephaly (complete or almost complete absence of cerebral hemispheres) and transposition of the great vessels (reversal of main vessels into heart); notwithstanding all proper care, the severity of the anomalies made the prognosis very pessimistic. Finding: no violation.

8. *Duarte, California.* January 10, 1983, complaint that the hospital denied the complainant's son admission to the hospital for a bone marrow transplant solely because of his handicapping condition, Down's syndrome. An investigation has been conducted. Administrative action has not been completed.

9. *Austin, Texas.* January 17, 1983, complaint that newborn babies with serious birth defects have not received proper care. An investigation has been conducted. Administrative action has not been completed.

10. *Lansing, Michigan.* January 24, 1983, complaint that a handicapped infant born to a surrogate mother was treated for a streptococci infection over the objections of the father who had told the hospital not to care for the child. OCR inquiry determined the hospital took immediate steps to obtain an appropriate court order to assure that needed treatment was provided, notwithstanding objections from the father. Finding: no violation.

11. *San Antonio, Texas.* March 2, 1983, complaint that deaths of a number of infants at two hospitals may have been related to discriminatory withholding of care. OCR investigation postponed at request of District Attorney assisting in grand jury criminal investigation.

12. *Houston, Texas.* March 10, 1983, complaint that five infants were denied proper care in a neonatal intensive care unit. The investigation has not been completed.

13. *Jackson, Michigan.* March 14, 1983, complaint from a mother that her son, who had Down's syndrome, died as a result of improper treatment. An investigation has been conducted. Administrative action not completed.

14. *Odessa, Texas.* March 18, 1983, hotline complaint that the hospital had failed to provide adequate medical care to a

premature infant who died in 1982. On-site investigation and review of medical records by OCR medical consultant found that the infant, born March 18, 1982, after a 25-26-week gestation period, suffered from extreme immaturity, and died March 20, 1982. Finding: no violation.

15. *Nashville, Tennessee.* March 22, 1983, hotline complaint that an infant had been denied sustenance for three days. Immediate contact revealed the infant was not a patient at the facility and the alleged attending physician was not a member of the attending or resident medical staff. This was verified by the patient census data, the facility's physician roster, and contact with the county medical society. This case was administratively closed due to an insufficient complaint.

16. *Nashville, Tennessee.* March 22, 1983, anonymous hotline complaint that 10 children were not receiving adequate medical treatment. Immediate on-site investigation, including an OCR medical consultant, determined that no child was in imminent danger; all children were receiving nutritional sustenance; and all children were receiving proper care. Finding: no violation.

17. *Fayette, Alabama.* March 22, 1983, anonymous hotline complaint that a handicapped infant was denied nourishment and allowed to die in an Alabama hospital in December 1982. The caller could provide no other information. Investigation has been conducted. Administrative action awaiting report from medical consultant.

18. *Waxahachie, Texas.* March 23, 1983, anonymous hotline complaint that between Christmas and February, a premature infant was denied treatment and allowed to die at a hospital in Texas. An investigation has been conducted. Administrative action not yet completed.

19. *Baltimore, Maryland,* March 23, 1983, hotline complaint that a premature infant was not being provided nourishment and heat. An immediate on-site investigation determined that the infant, weight 1 lb., ½ ounce at birth, was previable; the infant died several hours after birth; the infant had no congenital malformations or anomalies. Final administrative action on this case has not yet been taken.

20. *Newark, New Jersey.* March 27, 1983, anonymous hotline complaint that a premature infant, born as a result of a third trimester abortion, was not receiving adequate care. Immediate on-site investigation revealed that the premature infant weighed about 700 grams, and showed few signs of life. The infant was aggressively resuscitated, placed on intravenous feeding, and provided other life supporting treatment. Appropriate care was being provided. Finding: no violation.

21. *Rochester, New York.* March 29, 1983, hotline complaint that Siamese twin infants were being denied treatment. Immediate on-site investigation determined that team specialists examined the infants and concluded the conjoined female infant would not survive any attempt to separate them. Full intensive care was provided. The infants were placed on a respirator and given antibiotics, fluid and the necessary nutrition. At the time of the on-site, March 29, 1983, it was determined that there was no basis for seeking emergency remedial action. Final administrative action has not yet been completed.

22. *Seattle, Washington.* March 30, 1983, hotline complaint that an infant was being denied food and water and would not live much longer than a day or two. The caller had no identifying or other information. Immediate on-site inquiry determined there were no infants at the facility meeting the description of the complaint. The case was administratively closed due to insufficient complaint.

23. *Miami, Florida.* April 4, 1983, hotline complaint alleging (based upon information in the newspaper) parents of a premature infant and the attending physician decided not to allow the infant to be resuscitated. Immediate inquiry determined the infant had died prior to receipt of the complaint. The premature infant had multiple catastrophic conditions, including complete liquefaction of the brain. Final administrative action awaiting report of medical consultant.

24. *Decatur, Alabama.* April 6, 1983, hotline complaint from a parent that her child's condition was misdiagnosed by a particular physician during a 2½ year period. Inquiry determined that the child suffers from food allergies; the prognosis is excellent, the child at one time was believed,

apparently erroneously, to be retarded. This case was administratively closed because the inquiry failed to reveal information suggesting a possible violation of section 504.

25. *Melrose Park, Illinois.* April 8, 1983, anonymous hotline complaint. The caller provided no details concerning the infant's condition or treatment. Immediate telephone inquiry discovered no information to suggest a section 504 violation. This case was administratively closed due to an insufficient complaint.

26. *Charlotte, North Carolina.* April 10, 1983, hotline complaint that a premature infant died in July 1979 due to withholding of treatment. The caller could not provide any other information. Due to the length of time since the alleged discriminatory act and the lack of specific information, this case was administratively closed due to an insufficient complaint.

27. *Hyde Park, New York.* April 13, 1983, anonymous hotline complaint that the hospital would have let a baby with Down's syndrome die if the parents had not been aggressive and insisted on care being provided. The caller could provide no identifying information. This case was administratively closed due to an insufficient complaint.

28. *Coquille, Oregon.* April 13, 1983, hotline complaint that parents of a handicapped infant and the attending physican were going to withhold all treatment. Immediate on-site investigation, including medical consultant's review of medical records, determined the infant had a severe congenital central nervous system defect incompatible with life and not amenable to surgical correction; hospital provided supportive care and attempted to provide fluid orally, but did not attempt to provide intravenous fluids or arrange immediate transfer to a tertiary level neonatal intensive care unit for more specialized evaluations. The OCR medical consultant and the specialists at the tertiary care facility to which the infant was transferred three days after birth concluded that no course of treatment which was available would have avoided imminent death of this infant; the most that could have been expected from more aggressive care would have been to prolong the act of dying. The infant died 10 days after birth. Finding: no violation.

29. *Athens, Tennessee.* April 18, 1983, anonymous hotline complaint that an infant born at 28 weeks gestation was denied treatment and nourishment and allowed to die at a Tennessee hospital. The caller could give no identifying information. Investigation has been conducted. Administrative action awaiting report of medical consultant.

30. *Shreveport, Louisiana.* April 20, 1983, hotline complaint that a particular physician at the hospital certified three infants born alive as stillborn and refused to provide care to another infant. Investigation, including medical consultant review, found no medically beneficial treatment was withheld. Finding: no violation.

31. *Dayton, Ohio.* April 29, 1983, anonymous hotline complaint that an infant, identity unknown, weighing one pound and eight ounces was denied treatment and died. Inquiry revealed the deceased infant was premature (22 weeks gestation) and immature (organs were not developed); the infant had no anomalies; the hospital attempted to administer oxygen but the lungs were too small to function; no medically benefical treatment was withheld. This case was administratively closed due to the lack of information suggesting possible violation of section 504.

32. *Los Angeles, California.* May 17, 1983, complaint that infant, believed stillborn, lived several hours and may not have received proper care. Administrative action has not been completed.

33. *Daytona Beach, Florida.* May 19, 1983, hotline complaint that an infant with spina bifida may not be receiving medical treatment. Immediate contact with hospital and state agency and prompt on-site investigation indicated that the parents did not consent to surgery for the infant; on May 18, eight days after birth, the state agency obtained a court order to provide surgery, which was performed May 22, 1983. An investigation has been conducted. Administrative action awaits report of medical consultant.

34. *Baton Rouge, Louisiana.* May 23, 1983, hotline complaint that medical services were denied a premature infant, who died soon after birth. Investigation has been conducted. Administrative action has not been completed.

35. *Colorado Springs, Colorado.* June 21, 1983, hotline complaint from a nurse that an infant with myelomeningocele and paralyzed vocal chords was being denied necessary surgery. Immediate on-site investigation indicated substantial uncertainty on whether treatment for the myelomeningocele would be provided immediately; physicians were providing nutrition and supportive care and were awaiting the results of several tests on the infant. During the afternoon, hospital personnel were advised that an on-site investigation would be initiated that evening; that the state child protective services agency would be asked to also investigate; and that OCR would notify the Justice Department of the investigation. Also during the afternoon, the OCR medical consultant discussed the case with the attending physician. That evening corrective surgery was performed on the myelomeningocele. Investigation, including review by medical consultant, determined that no medically beneficial treatment was withheld on the basis of the infant's handicap. Finding: no violation.

36. *Brooklyn, New York.* June 23, 1983, complaint that premature infant who died in 1981 did not receive proper care. An investigation was conducted. Administrative action awaits report of medical consultant.

37. *Atlanta, Georgia.* June 27, 1983, hotline complaint that an infant, identity unknown, born with multiple anomalies was in a life-threatening situation because the doctors were planning to cease treatment of the infant. On-site investigation, June 28, indicated the premature infant, who weighed 950 grams at birth, received aggressive treatment, but the prognosis was not optimistic. At the time of the on-site investigation, it was determined there was no basis to seek emergency remedial action. Final administrative action is awaiting written report from medical consultant.

38. *Medford, Oregon.* July 7, 1983, anonymous hotline complaint that two infants died in 1982 because of improper medical treatment. The investigation has not been completed.

39. *Pinehurst, North Carolina.* July 21, 1983, hotline complaint that a three-week old infant with spina bifida and hydrocephalus would not live if surgical treatment was not pro-

vided. Immediate inquiry determined the appropriate surgery was performed July 8, 1983. Final administrative action has not been concluded.

40. *San Francisco, California.* August 2, 1983, hotline complaint that an infant with a cleft palate and heart defect was allowed to die at a California hospital in May 1979. The caller stated that a malpractice lawsuit is pending. The investigation has not been completed.

41. *Falls Church, Virginia.* August 9, 1983, hotline complaint that a baby, identity unknown, with possible brain damage, no ears or eyes, would not be given nourishment. A meeting with hospital officials failed to identify an infant meeting the description given by the complainant. An infant with somewhat similar circumstances was described; no information concerning this infant suggested a lack of appropriate care. Complaint refused to accept OCR calls seeking further information. This case was administratively closed due to an insufficient complaint.

42. *Wichita, Kansas.* August 11, 1983, complaint that infant whose body was discovered at incinerator site may have been denied proper treatment. An investigation has been conducted. Administrative action has not been completed.

43. *Lincoln, Nebraska.* August 25, 1983, hotline complaint that two premature infants did not receive appropriate care and died. The investigation has not been completed.

44. *Boynton Beach, Florida.* September 20, 1983, hotline complaint that two handicapped infants were allowed to die immediately following birth. The investigation has not been completed.

45. *Norfolk, Virginia.* September 21, 1983, complaint that infant born alive following an abortion was not being fed or treated. Inquiry determined infant died September 20, 1983. Final administrative action has not been completed.

46. *Boise, Idaho.* September 30, 1983, hotline complaint that an abandoned premature infant with no brain tissue might be withdrawn from life support. Immediate inquiry determined the State child protective services agency had obtained custody of the infant and had no plans to discontinue life support. Final administrative action has not been completed.

47. *Philadelphia, Pennsylvania.* October 16, 1983, hotline complaint that infant, age approximately six weeks, with spina bifida, who received surgery, was not receiving appropriate follow-up care. Inquiry initiated October 16. Decision made that circumstances did not suggest need for immediate remedial action. Final administrative action has not been completed.

48. *Long Island, New York.* October 19, 1983, complaint, based on newspaper article, that infant with spina bifida not receiving surgery due to refusal of parents to consent; legal proceedings had been initiated in State court. Inquiry initiated October 19. On October 27, HHS asked Department of Justice to commence legal action to overcome refusal of hospital to permit review of pertinent records. On November 2, legal action was commenced. On November 17, district court ruled against the government. Appeal filed November 18.

49. *Phoenix, Arizona.* November 7, 1983, anonymous hotline complaint that infant with spina bifida and other conditions not receiving surgery. Immediate inquiry intiated; records obtained; OCR medical consultant discussed case with attending physician and hospital review committee. Decision made not to refer case to Justice Department for emergency remedial action. Final administrative action not yet completed.

The Department believes three of these cases demonstrate the utility of the procedural mechanisms called for in the final rules. In the Robinson, Illinois, case (listed as case 2, above), for example, the involvement of the state child protective services agency, working in cooperation with HHS and the Justice Department, was the most important element in bringing about corrective surgery for the infant. The state agency received a report from the hospital administrator pursuant to the state child protective services statute. Had there been no governmental involvement in the case, the outcome might have been much less favorable. Media reports one year later indicate the child's development was proceeding very well, with leg braces adequately compensating for the child's impairment.

In the Daytona Beach, Florida, case (listed as case 33, above), action by the state child protective services agency,

like that called for in the final rules, brought about needed corrective surgery. Without this action, the infant might have died or suffered more severe impairments.

In the Colorado Springs, Colorado, case (listed as case 35, above) the prompt involvement of HHS, acting upon a complaint from a nurse, may have contributed to the decision to provide corrective surgery. Because the decisionmaking process was in progress at the time the OCR inquiry began, it is impossible to say the surgery would not have been provided without this involvement. However, the involvement of OCR and the OCR medical consultant was cooperatively received by the hospital and apparently constructive.

Although no case has resulted in a finding of discriminatory withholding of medical care, the Department believes these cases provide additional documentation of the need for governmental involvement and the appropriateness of the procedures established by the final rules.

E. OTHER ISSUES

Self-Evaluation

Among the questions on which the July 5 notice of proposed rulemaking solicited comments was question 1:

> Should recipients providing health care services to infants be required to perform a self-evaluation, pursuant to 45 CFR 84.6(c)(1), with respect to their policies and practices concerning health services to handicapped infants?

A number of commenters expressed support for this requirement. Some commenters expressed the view that self-evaluations would be helpful and should be conducted, but they should not be a federal regulatory mandate. Some commenters suggested that if this were to be a requirement, it should be through mechanisms other than section 504, such as voluntary accreditation standards or Medicare conditions of participation.

Some commenters opposed a self-evaluation requirement on the grounds it would likely be unproductive. For example:

> Americans United for Life is skeptical of any approach to the enforcement of section 504 that relies on

the cooperation of those being regulated. Encouraging hospitals to perform "*self*-evaluation" is not likely to lead to *accurate* evaluation.

Response

The Department has not adopted a self-evaluation requirement as part of the final rules. The Department believes this function will be most effectively carried out in connection with the activities of Infant Care Review Committees encouraged by the final rules, and therefore will not seek to impose uniform standards for self-evaluations.

Information to Parents

Among the questions on which the July 5 notice of proposed rulemaking solicited comments was question 2:

> Should such recipients be required to identify for parents of handicapped infants born in their facilities those public and private agencies in the geographical vicinity that provide services to handicapped infants?

A great many commenters expressed support for such a requirement on the ground that before parents are put into a position of having to make very difficult decisions concerning care for their handicapped child, the parents should be aware of the health and social services agencies and organizations and parental support groups available in the community. Other commenters opposed this requirement. Some commenters expressed the view that hospitals should provide this information as part of their own policies and procedures, but that it would be counterproductive to seek to impose rigid, uniform regulatory requirements in this regard.

Among those supporting such a requirement was the Spina Bifida Association of America (SBAA):

> The SBAA strongly supports such a requirement; it might be the most important influential aspect of the entire regulation.
>
> Parents of a newborn spina bifida child are expected to make rational life and death decisions when what was expected to be a joyous time has instead become an occasion for confronting the concerns of the unknown. The decisions must be made quickly and under great stress.

> Dr. Rosalyn Darling, a member of SBAA's Professional Advisory Committee, has written that decisions are often made by physicians and individuals who have very little contact with the disabled community; consequently, decisions concerning treatment are often "stacked" against the newborn with a problem. Parents naturally turn to their physician for guidance, but he or she may have only outdated and unwarrantedly pessimistic information about spina bifida. Even if the physician is well-informed about the available treatment, he or she is rarely aware of the supportive services in the community or equipped to give the support and counselling that others who have gone through the same experience can't provide.
>
> Clearly, new parents of a disabled child need the names of agencies and support groups available to assist the family unit. Other parents who have gone through the same situation can then share their knowledge of the disability and its treatment and give comfort and assistance.

The American Speech-Language-Hearing Association, which represents 39,000 speech-language pathologists and audiologists nationwide, stated:

> [P]arents and physicians are largely unaware of what educational, habilitative, and rehabilitative services are available for handicapped children, how much success handicapped children receiving these services can have, the obligation of states to educate handicapped children, the extent of research now going on regarding handicapped children, and other federal, state and local governmental commitments to the handicapped. Unfortunately, physicians have all that they can do to maintain currency with medical information and are, therefore, frequently ill-informed as to what can be done for handicapped infants....
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> . .Recipients should be required to provide complete information to the parent about the appropriate handicap. This would include not only identification of public and private agencies that provide services to handicapped infants, but (1) detailed information on the handicap itself; (2) discussion of the educational and rehabilitation potential; (3) discussion of alternative care

> options such as foster homes, adoption, etc.; (4) identification of parent support groups; and (5) discussion of expectations for a self-sufficient future life. In providing the required information the recipient should use individuals knowledgeable about the handicap, including professionals, associations and parents of handicapped children. For example, the American Speech-Language-Hearing Association and its consumer affiliate, the National Association of Hearing and Speech Action (NAHSA) maintains a Help line (800-638-8255) that can be used to obtain information on (1) speech-language pathology and audiology services available in any area of the United States, (2) speech, language and hearing disorders, and (3) other agencies serving the communicatively handicapped. NAHSA provides informational brochures .... Many professional associations have similar documents that would be helpful to recipients.

Among those opposing a requirement that recipients provide information to parents was Georgetown University Hospital, Washington, D.C. As an alternative, the hospital proposed:

> DHHS should undertake the responsibility of providing a federal office charged with the task of identifying for parents of handicapped children those public and private agencies in the geographical vicinity of the parent's residence that provide service of handicapped infants, and for providing the necessary financial assistance to acquire such services. Hospitals should be required to furnish parents with a telephone number, and/or address of this federal office.

Response

The Department believes it is extremely important for parents of handicapped newborn infants to receive detailed information on the availability of health and social services for handicapped children in the communities. However, the Department has concluded the most effective way to advance this goal is not through an attempt to impose detailed regulatory requirements that would be very difficult to monitor and enforce.

Rather, the Department has undertaken several initiatives, discussed above in the preamble, to improve the furnishing of information to parents. In addition, this should be a central focus of the activities of the Infant Care Review Committees, which, under the model set forth in the final rules, include participation by representatives of disability groups or disability experts.

VI. Regulatory Information

Severability

It is the Secretary's intent that should any subsection, paragraph, clause, or provision of this rule be declared by a court of competent jurisdiction to be invalid, the remainder of the rule, not expressly so declared invalid, shall continue in effect.

Regulatory Impact Analysis

This proposed rule has been reviewed under Executive Order 12291. It is not a major rule as defined by the Order because it does not have an effect on the economy of $100 million or more or meet the other definitional criteria contained in the Order, and thus does not require a regulatory impact analysis.

Regulatory Flexibility Analysis

The Regulatory Flexibility Act (Pub. L. 96-354) requires the Federal government to anticipate and reduce the impact of rules and paperwork requirements on small businesses and other small entities. For each rule with a "significant impact on a substantial number of small entities" an analysis must be prepared describing the rule's impact on small entities.

The Secretary certifies that the final rules do not have a significant impact on a substantial number of small entities. As it relates to hospitals, the primary requirement of the final rules is to post an informational notice, which has no significant impact on the hospitals. The requirements concerning expedited access to records and expedited action to effect compliance also, as explained above, have no significant impact. Requirements in the final rules relating to state child protective services agencies have no substantial impact

on those agencies, because those requirements, as explained above, are fully consistent with normal procedures of those agencies and existing regulatory requirements.

Matters addressed in the guidelines included in the final rules are not requirements of the rules. They reflect interpretations and procedures of the Department pursuant to the statute, existing regulations, and existing procedures.

Therefore, a regulatory flexibility analysis is not required.

Paperwork Reduction Act

Section 84.55(c) of the final rules contains information collection requirements. These requirements were submitted to the Office of Management and Budget for review under section 3504(h) of the Paperwork Reduction Act of 1980, and approved for use through September 30, 1986. The OMB No. is 0990-0114.

Department of Justice Review

Pursuant to Executive Order 12250, these final rules have been reviewed and approved by the Department of Justice.

List of Subjects in 45 CFR Part 84

Civil rights, Education of handicapped, Handicapped, Physically handicapped.

Dated: December 30, 1983.

Approved:

Margaret M. Heckler,

Secretary.

PART 84—[AMENDED]

The authority citation for Part 84 is as follows:

> **Authority:** Sec. 504, Rehabilitation Act of 1973, Pub. L. 93-112, 87 Stat. 394 (29 U.S.C. 794974) [*sic*]; sec. 111(a), Rehabilitation Act Amendments of 1974, Pub. L. 93-516, 88 Stat. 1619 (29 U.S.C. 706); sec. 606, Education of the Handicapped Act (20 U.S.C. 1405), as amended by Pub. L. 94-142, 89 Stat. 795; sec. 321, Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, 84 Stat. 182 (42 U.S.C. 4581), as amended; sec. 497, Drug Abuse Office and Treatment Act of 1972, 86 Stat. 78 (21 U.S.C. 1174), as amended.

For the reasons set forth in the preamble:

1. 45 CFR Part 84 is amended by inserting after § 84.54 the following new § 84.55:

§ 84.55 Procedures relating to health care for handicapped infants

(a) *Infant Care Review Committees.* The Department encourages each recipient health care provider that provides health care services to infants in programs receiving Federal financial assistance to establish an Infant Care Review Committee (ICRC) to assist the provider in delivering health care and related services to infants and in complying with this part. The purpose of the committee is to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases. While the Department recognizes the value of ICRC's in assuring appropriate medical care to infants, such committees are not required by this section. An ICRC should be composed of individuals representing a broad range of perspectives, and should include a practicing physician, a representative of a disability organization, a practicing nurse, and other individuals. A suggested model ICRC is set forth in paragraph (f) of this section.

(b) *Posting of informational notice.* (1) Each recipient health care provider that provides health care services to infants in programs or activities receiving Federal financial assistance shall post and keep posted in appropriate places an informational notice.

(2) The notice must be posted at location(s) where nurses and other medical professionals who are engaged in providing health care and related services to infants will see it. To the extent it does not impair accomplishment of the requirement that copies of the notice be posted where such personnel will see it, the notice need not be posted in area(s) where parents of infant patients will see it.

(3) Each health care provider for which the content of the following notice (identified as Notice A) is truthful may use Notice A. For the content of the notice to be truthful: (i) The provider must have a policy consistent with that stated in the notice; (ii) the provider must have a procedure for review of treatment deliberations and decisions to which the

notice applies, such as (but not limited to) an Infant Care Review Committee; and (iii) the statements concerning the identity of callers and retaliation are truthful.

Notice A:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

(4) Health care providers other than those described in paragraph (b)(3) of this section must post the following notice (identified as Notice B):

Notice B:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, applies to programs or activities receiving

Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Federal regulations prohibit retaliation by this hospital against any person who provides information about possible violations.

(5) The notice may be no smaller than 5 by 7 inches, and the type size no smaller than that generally used for similar internal communications to staff. The recipient must insert the specified information on the notice it selects. Recipient hospitals in Washington, D.C. must list 863-0100 as the telephone number for HHS. No other alterations may be made to the notice. Copies of the notices may be obtained from the Department of Health and Human Services upon request, or the recipient may produce its own notices in conformance with the specified wording.

(c) Responsibilities of recipient state child protective services agencies. (1) Within 60 days of the effective date of this section, each recipient state child protective services agency shall establish and maintain in written form methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants. These methods of administration and procedures shall include:

(i) A requirement that health care providers report on a timely basis to the state agency circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants;

(ii) A method by which the state agency can receive reports of suspected unlawful medical neglect of handicapped infants from health care providers, other individuals, and the Department on a timely basis;

(iii) Immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports;

(iv) Provision of child protective services to such medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the provision of necessary nourishment and medical treatment; and

(v) Timely notification to the responsible Department official of each report of suspected unlawful medical neglect involving the withholding, solely on the basis of present or anticipated physical or mental impairments, of treatment or nourishment from a handicapped infant who, in spite of such impairments, will medically benefit from the treatment or nourishment, the steps taken by the state agency to investigate such report, and the state agency's final disposition of such report.

(2) Whenever a hospital at which an infant who is the subject of a report of suspected unlawful medical neglect is being treated has an Infant Care Review Committee (ICRC) the Department encourages the state child protective services agency to consult with the ICRC in carrying out the state agency's authorities under its state law and methods of administration. In developing its methods of administration and procedures, the Department encourages child protective services agencies to adopt guidelines for investigations similar to those of the Department regarding the involvement of ICRC's.

(The provisions of § 84.55(c) have been approved by the Office of Management and Budget pursuant to the Paperwork Reduction Act. The OMB No. is 0990-0114).

(d) *Expedited access to records.* Access to pertinent records and facilities of a recipient pursuant to 45 CFR 80.6(c) (made applicable to this part by 45 CFR 84.61) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

(e) *Expedited action to effect compliance.* The requirement of 45 CFR 80.8(d)(3) pertaining to notice to recipients prior to the initiation of action to effect compliance (made applicable to this part by 45 CFR 84.61) shall not apply when, in the judgment of the responsible Department official, immediate action to effect compliance is necessary to protect

the life or health of a handicapped individual. In such cases the recipient will, as soon as practicable, be given oral or written notice of its failure to comply, of the action to be taken to effect compliance, and its continuing opportunity to comply voluntarily.

(f) *Model Infant Care Review Committee.* Recipient health care providers wishing to establish Infant Care Review Committees should consider adoption of the following model. This model is advisory. Recipient health care providers are not required to establish a review committee or, if one is established, to adhere to this model. In seeking to determine compliance with this part, as it relates to health care for handicapped infants, by health care providers that have an ICRC established and operated substantially in accordance with this model, the Department will, to the extent possible, consult with the ICRC.

(1) *Establishment and purpose.* (i) The hospital establishes an Infant Care Review Committee (ICRC) or joins with one or more other hospitals to create a joint ICRC. The establishing document will state that the ICRC is for the purpose of facilitating the development and implementation of standards, policies and procedures designed to assure that, while respecting reasonable medical judgments, treatment and nourishment not be withheld, solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite of such impairments, will benefit medically from the treatment or nourishment.

(ii) The activities of the ICRC will be guided by the following principles:

(A) The interpretative guidelines of the Department relating to the applicability of this part to health care for handicapped infants.

(B) As stated in the "Principles of Treatment of Disabled Infants" of the coalition of major medical and disability organizations, including the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association, and others:

> When medical care is clearly beneficial, it should always be provided. When appropriate medical care is

not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

(C) As stated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

> This (standard for providing medically beneficial treatment) is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

(iii) The ICRC will carry out its purposes by:

(A) Recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for ICRC action for specific categories of life-threatening conditions affecting infants;

(B) Providing advice in specific cases when decisions are being considered to withhold or withdraw from infant life-sustaining medical or surgical treatment; and

(C) Reviewing retrospectively on a regular basis infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.

(2) *Organization and staffing.* The ICRC will consist of at least 7 members and include the following:

(i) A practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon),

(ii) A practicing nurse,

(iii) A hospital administrator,

(iv) A representative of the legal profession,

(v) A representative of a disability group, or a developmental disability expert,

(vi) A lay community member, and

(vii) A member of a facility's organized medical staff, who shall serve as chairperson.

In connection with review of specific cases, one member of the ICRC shall be designated to act as "special advocate" for the infant, as provided in paragraph (f)(3)(ii)(E) of the section. The hospital will provide staff support for the ICRC, including legal counsel. The ICRC will meet on a regular basis, or as required below in connection with review of specific cases. It shall adopt or recommend to the appropriate hospital official or body such administrative policies as terms of office and quorum requirements. The ICRC will recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the ICRC and its availability on a 24-hour basis.

(3) *Operation of ICRC—(i) Prospective policy development.* (A) The ICRC will develop and recommend for adoption by the hospital institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These will include guidelines for management of specific types of cases or diagnoses, for example, Down's syndrome and spina bifida, and procedures to be followed in such recurring circumstances as, for example, brain death and parental refusal to consent to life-saving treatment. The hospital, upon recommendation

of the ICRC, may require attending physicians to notify the ICRC of the presence in the facility of an infant with a diagnosis specified by the ICRC, e.g., Down's syndrome and spina bifida.

(B) In recommending these policies and guidelines, the ICRC will consult with medical and other authorities on issues involving disabled individuals, e.g., neonatologists, pediatric surgeons, county and city agencies which provide services for the disabled, and disability advocacy organizations. It will also consult with appropriate committees of the medical staff, to ensure that the ICRC policies and guidelines build on existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The ICRC will also inform and educate hospital staff on the policies and guidelines it develops.

(ii) *Review of specific cases.* In addition to regularly scheduled meetings, interim ICRC meetings will take place under specified circumstances to permit review of individual cases. The hospital will, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice.

(A) Interim ICRC meetings will be convened within 24 hours (or less if indicated) when there is disagreement between the family of an infant and the infant's physician as to the withholding or withdrawal of treatment, when a preliminary decision to withhold or withdraw life-sustaining treatment has been made in certain categories of cases identified by the ICRC, when there is disagreement between members of the hospital's medical and/or nursing staffs, or when otherwise appropriate.

(B) Such interim ICRC meetings will take place upon the request of any member of the ICRC or hospital staff or parent or guardian of the infant. The ICRC will have procedures to preserve the confidentiality of the identity of persons making such requests, and such persons shall be protected from reprisal. When appropriate, the ICRC or a designated member will inform the requesting individual of the ICRC's recommendation.

(C) The ICRC may provide for telephone and other forms of review when the timing and nature of the case, as

identified in policies developed by the ICRC, make the convening of an interim meeting impracticable.

(D) Interim meetings will be open to the affected parties. The ICRC will ensure that the interests of the parents, the physician, and the child are fully considered; that family members have been fully informed of the patient's condition and prognosis; that they have been provided with a listing which describes the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the ICRC; and that the ICRC will facilitate their access to such services and groups.

(E) To ensure a comprehensive evaluation of all options and factors pertinent to the committee's deliberations, the chairperson will designate one member of the ICRC to act, in connection with that specific case, as special advocate for the infant. The special advocate will seek to ensure that all considerations in favor of the provision of life-sustaining treatment are fully evaluated and considered by the ICRC.

(F) In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the family's wishes will be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the ICRC, after due deliberation, agrees with the family, the ICRC will recommend that the treatment be withheld. When there is physician/family disagreement and the family refuses consent, but the ICRC disagrees with the family, the ICRC will recommend to the hospital board or appropriate official that the case be referred immediately to an appropriate court or child protective agency, and every effort shall be made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action. The ICRC will also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdrawn, but the ICRC disagrees.

(iii) *Retrospective record review.* The ICRC, at its regularly-scheduled meeting, will review all records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed by the ICRC, unless the case was previously before the ICRC pursuant to paragraph (f)(3)(ii) of this section. If the ICRC finds that a deviation was made from the institutional policies in a given case, it shall conduct a review and report the findings to appropriate hospital personnel for appropriate action.

(4) *Records.* The ICRC will maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records will be kept in accordance with institutional policies on confidentiality of medical information. They will be made available to appropriate government agencies, or upon court order, or as otherwise required by law.

Amendment to Table of Contents

2. The table of contents to 45 CFR Part 84 is amended by striking the designation of "84.55-84.60 [Reserved]" and by inserting in lieu thereof, the following:

Sec.
84.55 Procedures relating to health care for handicapped infants.
84.56-84.60 [Reserved]

3. 45 CFR Part 84 is amended by inserting after Appendix B the following new appendix:

Appendix C—Guidelines Relating to Health Care for Handicapped Infants.

(a) *Interpretative guidelines relating to the applicability of this part to health care for handicapped infants.* The following are interpretative guidelines of the Department set forth here to assist recipients and the public in understanding the Department's interpretation of section 504 and the regulations contained in this part as applied to matters concerning health care for handicapped infants. These interpretative guidelines are illustrative; they do not independently establish rules of conduct.

(1) With respect to programs and activities receiving Federal financial assistance, health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.

(2) Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant.

(3) In determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.

(4) Section 504 and the provisions of this part are not applicable to parents (who are not recipients of Federal financial assistance). However, each recipient health care provider must in all aspects of its health care programs receiving Federal financial assistance provide health care and related services in a manner consistent with the requirements of section 504 and this part. Such aspects includes decisions on whether to report, as required by State law or otherwise, to the appropriate child protective services agency a suspected instance of medical neglect of a child, or to take other action to seek review or [sic] parental decisions to withhold consent for medically indicated treatment. Whenever parents make a decision to withhold consent for medically beneficial treatment or nourishment, such recipient providers may not, solely on the basis of the infant's present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such incidents to the child protective services agency or to seek judicial review.

(5) The following are examples of applying these interpretative guidelines. These examples are stated in the context of decisions made by recipient health care providers. Were these decisions made by parents, the guideline stated in section (a)(4) would apply. These examples assume no facts or complications other than those stated. Because every case must be examined on its individual facts, these are merely illustrative examples to assist in understanding the framework for ap-

plying the nondiscrimination reuqirements of section 504 and this part.

(i) Withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome when the withholding is based upon the anticipated future mental retardation of the infant and there are no medical contraindications to the surgery that would otherwise justify withholding the surgery would constitute a discriminatory act, violative of section 504.

(ii) Withholding of treatment for medically correctable physical anomalies in children born with spina bifida when such denial is based on anticipated mental impairment, paralysis or incontinence of the infant, rather than on reasonable medical judgments that treatment would be futile, too unlikely of success given complications in the particular case, or otherwise not of medical benefit to the infant, would constitute a discriminatory act, violative of section 504.

(iii) Withholding of medical treatment for an infant born with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.

(iv) Withholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504.

(b) *Guidelines for HHS investigations relating to health care for handicapped infants.* The following are guidelines of the Department in conducting investigations relating to health care for handicapped infants. They are set forth here to assist recipients and the public in understanding applicable investigative procedures. These guidelines do not establish rules of conduct, create or affect legally enforceable rights of any person, or modify existing rights, authorities or responsibilities pursuant to this part. These guidelines reflect the Department's recognition of the special circumstances presented in connection with complaints of suspected life-threatening noncompliance with this part involving health care for handicapped infants. These guidelines do not apply to other investigations pursuant

to this part, or other civil rights statutes and rules. Deviations from these guidelines may occur when, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant.

(1) Unless impracticable, whenever the Department receives a complaint of suspected life-threatening noncompliance with this part in connection with health care for a handicapped infant in a program or activity receiving Federal financial assistance, HHS will immediately conduct a preliminary inquiry into the matter by initiating telephone contact with the recipient hospital to obtain information relating to the condition and treatment of the infant who is the subject of the complaint. The preliminary inquiry, which may include additional contact with the complainant and a requirement that pertinent records be provided to the Department, will generally be completed within 24 hours (or sooner if indicated) after receipt of the complaint.

(2) Unless impracticable, whenever a recipient hospital has an Infant Care Review Committee, established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the Department will, as part of its preliminary inquiry, solicit the information available to, and the analysis and recommendations of, the ICRC. Unless, in the judgment of the responsible Department official, other action is necessary to protect the life or health of a handicapped infant, prior to initiating an on-site investigation, the Department will await receipt of this information from the ICRC for 24 hours (or less if indicated) after receipt of the complaint. The Department may require a subsequent written report of the ICRC's findings, accompanied by pertinent records and documentation.

(3) On the basis of the information obtained during preliminary inquiry, including information provided by the hospital (including the hospital's ICRC, if any), information provided by the complainant, and all other information obtained, the Department will determine whether there is a need for an on-site investigation of the complaint. Whenever the Department determines that doubt remains that the recipient hospital or some other recipient is in compliance with this part or additional documentation is desired to substantiate a conclu-

sion, the Department will initiate an on-site investigation or take some other appropriate action. Unless impracticable, prior to initiating an on-site investigation, the Department's medical consultant (referred to in paragraph 6) will contact the hospital's ICRC or appropriate medical personnel or the recipient hospital.

(4) In conducting on-site investigations, when a recipient hospital has an ICRC established and operated substantially in accordance with the provisions of 45 CFR 84.55(f), the investigation will begin with, or include at the earliest practicable time, a meeting with the ICRC or its designees. In all on-site investigations, the Department will make every effort to minimize any potential inconvenience or disruption, accommodate the schedules of health care professionals and avoid making medical records unavailable. The Department will also seek to coordinate its investigation with any related investigations by the state child protective services agency so as to minimize potential disruption.

(5) It is the policy of the Department to make no comment to the public or media regarding the substance of a pending preliminary inquiry or investigation.

(6) The Department will obtain the asistance of a qualified medical consultant to evaluate the medical information (including medical records) obtained in the course of a preliminary inquiry or investigation. The name, title and telephone number of the Department's medical consultant will be made available to the recipient hospital. The Department's medical consultant will, if appropriate, contact medical personnel of the recipient hospital in connection with the preliminary inquiry, investigation or medical consultant's evaluation. To the extent practicable, the medical consultant will be a specialist with respect to the condition of the infant who is the subject of the preliminary inquiry or investigation. The medical consultant may be an employee of the Department or another person who has agreed to serve, with or without compensation, in that capacity.

(7) The Department will advise the recipient hospital of its conclusions as soon as possible following the completion of a preliminary inquiry or investigation. Whenever final administrative findings following an investigation of a complaint of suspected life-threatening noncompliance cannot be made promptly, the Depart-

ment will seek to notify the recipient and the complainant of the Department's decision on whether the matter will be immediately referred to the Department of Justice pursuant to 45 CFR 80.8.

(8) Except as necessary to determine or effect compliance, the Department will (i) in conducting preliminary inquiries and investigations, permit information provided by the recipient hospital to the Department to be furnished without names or other identifying information relating to the infant and the infant's family; and (ii) to the extent permitted by law, safeguard the confidentiality of information obtained.

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[47 Fed. Reg. 26027 (June 16, 1982)]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Discriminating Against the Handicapped by Withholding Treatment or Nourishment, Notice of Health Care Providers

May 18, 1982

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

This notice is intended to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). Section 504 provides that "No otherwise qualified handicapped individual * * * shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance * * *" Implementing regulations issued by the Department of Health and Human Services make clear that this statutory prohibition applies in the provision of health services [45 CFR 84.52] and that conditions such as Down's syndrome are handicaps within the meaning of section 504 (45 CFR 84.3 (j)).

Under section 504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

(1) The withholding is based on the fact that the infant is handicapped; and

(2) The handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, a recipient may not lawfully decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

We recognize that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent

has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization. 45 CFR 84.4(b)(1)(v). Recipients must accordingly insure that they do not violate section 504 by facilitating discriminatory conduct.

In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.
- Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.
- Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance. Moreover, section 504 does not limit the continued enforcement of State laws prohibiting the neglect of children, requiring medical treatment, or imposing similar responsibilities.

Betty Lou Dotson,
Director, Office for Civil Rights.

[FR Doc. 83-1825a Filed 6-14-82. 3:45 pm]
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UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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84 CIV. 1724-CLB

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PLAINTIFFS,

-against-

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DEFENDANT.

COMPLAINT FOR DECLARATORY AND INJUNCTIVE RELIEF

Preliminary Statement

1. This action is brought on behalf of affected physicians and medical and other health care associations as representatives of their members. It seeks to declare invalid and permanently enjoin final rules on "Procedures and Guidelines Relating to Health Care for Handicapped Infants" [hereinafter "the Final Regulation"]. These rules were issued by the Secretary of the United States Department of Health and Human Services [hereinafter "HHS"] on January 12, 1984 and became effective on February 13, 1984. 49 Fed. Reg. 1621. The Final Regulation was promulgated under the putative authority of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794. That statute proscribes discrimination against handicapped individuals under any program or activity receiving Federal financial assistance. This action also seeks to declare invalid and enjoin all investigation and enforcement actions which HHS is presently conducting and may in the future conduct under the putative authority of Section 504 with respect to alleged discrimination in treatment decisions involving impaired newborn infants.

2. This Final Regulation, and the other activities carried out by HHS under color of Section 504, involve direct Federal investigations, or Federally compelled state investigations, into one of the most sensitive, complex and personal areas in which parents must make decisions about their infant children in consultation with physicians: what sort of treatment, if any, should be given newborn infants suffering severe mental or physical impairment? This intrusion has recently been held unlawful by the United States Court of Appeals for the Second Circuit which ruled that Section 504 does not extend to treatment involving impaired newborn infants. *United States* v. *University Hospital*, No. 83-6343 (2nd Cir. February 23, 1984).

3. The Final Regulation requires all hospitals receiving Federal financial assistance to publish a uniform notice which improperly states that Section 504 applies to treatment decisions involving impaired newborns. This legally incorrect notice has the purpose and effect of stimulating complaints about parents' treatment decisions made on behalf of their children in consultation with their physicians. These complaints may be lodged with hospital, state or Federal authorities. The Final Regulation also requires physicians and other health professionals to violate their confidential relationship with parents as guardians of their patient children and to report to state child protection agencies "suspected instances" of "neglect" in parental decisions involving treatment of their impaired newborns. These state child protection agencies are, in turn, required by the Final Regulation to investigate all reports about parental treatment decisions involving impaired newborns, to invade confidential physician-patient records, and to intrude on the confidential physician-patient relationship by conducting interviews with the family's treatment team. The Final Regulation authorizes similar, duplicative Federal investigations into such treatment decisions. Finally, it uses Federal power to force state agencies to establish procedures for taking actions, according to state law processes and state law standards, that are aimed at removing the parent as ultimate treatment decision-maker for the impaired newborn—and it allows the Federal government to second-guess that state agency decision about whether or not to initiate actions against parents.

4. The Final Regulation and HHS' other investigations into treatment involving impaired newborns injure infants because medical personnel are diverted from provision of treatment to responding to investigations triggered without any standards. These HHS actions injure parents who are placed in tragic, stressful situations by vitiating their autonomy to make decisions for their children, subjecting them to improper investigations, violating their confidential relationship with physicians of their choice, and undermining their confidence in their physicians, in their hospitals and in the medical profession. These actions also injure physicians by forcing them to take actions under Federal dictates and standards that are inconsistent with medical practice, medical knowledge and medical ethics. Finally, HHS' actions injure recipients of Federal health care funds by forcing them to publish a legally incorrect notice which encourages harassing complaints about the patients in their facility and by requiring health care professionals in their employ to take actions which are inconsistent with medical practice, medical knowledge and medical ethics.

5. Both the Final Regulation and other enforcement activities by HHS under Section 504 are unlawful. They exceed the scope of authority granted to the Secretary of HHS by the Congress. Moreover, they constitute masive and unjustified invasions of the privacy rights of parents acting in the best interests of their impaired children in consultation with physicians of their choice. The Final Regulation is also unlawful as arbitrary and capricious agency action which constitutes an abuse of discretion and is not otherwise in accordance with law.

Jurisdiction and Venue

6. This action arises under Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 794); the Administrative Procedure Act (5 U.S.C. § 551 *et seq.*); and the First, Fifth and Ninth Amendments to the Constitution of the United States.

7. This court has subject matter jurisdiction pursuant to 28 U.S.C. § 1331. This Court is authorized to issue appropriate declaratory relief under 28 U.S.C. §§ 2201-2202.

8. Venue is proper in this district under 28 U.S.C. § 1391.

Plaintiffs

9. Plaintiff American Medical Association [hereinafter "AMA"] is a national professional organization whose membership includes approximately 256,000 physicians, osteopaths and medical and osteopathic students. The AMA's membership includes over 10,000 pediatricians (of whom 294 are neonatalogists or perinatalogists) and over 14,000 obstetricians and gynecologists. These member physicians—in particular, pediatricians, obstetricians and gynecologists—practice their specialities in hospitals located in every state and the District of Columbia. The AMA's headquarters are in Chicago, Illinois, and the AMA maintains local offices in Washington, D.C. and New York, New York. The AMA is suing in its representative capacity on behalf of the thousands of physicians nationwide who will be affected by the challenged actions of Defendant. The AMA's purposes include promotion of quality patient care, protection of the ability of physicians to practice medicine according to their best professional judgment and protection of the confidentiality of the physician-patient relationship and of medical records.

10. Plaintiff American Hospital Association [hereinafter "AHA"] is a national organization whose membership includes approximately 6,000 of the nation's 7,000 hospitals. AHA is suing in its representative capacity on behalf of its members, the vast preponderance of which receive Federal financial assistance as defined in the Final Regulation. AHA's purposes include promotion of quality medical care provided to patients and protection of the confidentiality of medical records kept by health care providers for individual patients.

11. Plaintiff Hospital Association of New York State [hereinafter "HANYS"] is a not-for-profit association whose membership includes approximately 300 non-profit voluntary and public hospitals and health care institutions located in New York State. The vast preponderance of its members receive Federal financial assistance as defined in the Final Regulation, and HANYS is suing in its representative capacity on their behalf. HANYS' purposes include promoting

quality of care provided to patients and maintaining the confidentiality of medical records kept by health care providers for individual patients.

12. Plaintiff American College of Obstetricians and Gynecologists [hereinafter "ACOG"] is a private, voluntary, not-for-profit organization of physicians specializing in obstetrics and gynecology. ACOG's membership includes over 24,000 physician members representing approximately 90 percent of American obstetricians and gynecologists. ACOG is suing in its representative capacity on behalf of these thousands of obstetricians and gynecologists nationwide who will be affected by the challenged actions of Defendant. ACOG's purposes include promotion of high quality patient care in the field of obstetrics and gynecology, protection of confidential physician-patient relationships, and development of professional standards for the practice of obstetrics and gynecology.

13. Plaintiff Association of American Medical Colleges [hereinafter "AAMC"] is a national professional organization whose membership includes approximately 127 medical schools, 400 teaching hospitals and 76 academic societies in the United States. AAMC is suing in its representative capacity on behalf of its members, the vast preponderance of which receive Federal financial assistance as defined in the Final Regulation or which represent physicians who practice medicine in institutions that receive Federal financial assistance as defined in the Final Regulation. AAMC's purposes include the advancement of medical education and the improvement of health care in the United States.

14. Plaintiff American Academy of Family Physicians [hereinafter "AAFP"] is a national professional association whose membership includes approximately 56,000 family physicians and medical students. AAFP is suing in its representative capacity on behalf of these thousands of family physicians and medical students nationwide who will be affected by the challenged actions of Defendant. AAFP's purposes include promotion of excellence in health care and in the delivery and care of newborn infants.

15. Plaintiff Hubert A. Ritter, M.D., is a practicing obstetrician/gynecologist. He is Secretary-Treasurer of the

AMA. He is a member of the medical staffs of St. Louis University Hospital, St. Mary's Health Center and Deaconness Hospital. These health care institutions receive Federal financial assistance as defined in the Final Regulation. He is a Clinical Professor at St. Louis University's School of Medicine in the Department of Obstetrics and Gynecology.

16. Plaintiff Rita Gilman Harper, M.D., is a practicing neonatalogist. She is Chief of the Division of Perinatal Medicine at North Shore University Hospital in Manhasset, New York, and is a consultant in Perinatal Medicine at several other hospitals in the New York area. These hospitals receive Federal financial assistance as defined in the Final Regulation. She is Associate Professor of Pediatrics and Obstetrics and Gynecology at Cornell University Medical College, and is a member of the AMA, the American Pediatric Society and the American Academy of Pediatrics.

17. Plaintiff Peter A. M. Auld, M.D., is a practicing neonatalogist. He is Director of the Perinatalogy Center at New York Hospital in New York, New York. New York Hospital receives Federal financial assistance as defined in the Final Regulation. He is a member of the AMA, ACOG and the American Academy of Pediatrics.

18. Plaintiff Roy Howard Petrie, M.D., is a practicing obstetrician/gynecologist. He is Associate Professor of Obstetrics and Gynecology (Maternal Fetal Medicine) and Director of Obstetrical and Gynecological Education at the College of Physicians and Surgeons of Columbia University at the Columbia-Presbyterian Medical Center. This health care institution receives Federal financial assistance as defined in the Final Regualtion. He is a member of the AMA, ACOG, and the New York Obstetrical Society. He is President of the New York Perinatal Society and the Society of Perinatal Obstetricians.

Defendant

19. Defendant Margaret M. Heckler [hereinafter "Defendant"] is Secretary of the United States Department of Health and Human Services. As Secretary of HHS, she is the Federal official responsible for promulgation and imple-

mentation of the Final Regualtion and for other conduct which are the subjects of this action.

Regulatory and Judicial Background

20. The Final Regulation is promulgated pursuant to Section 504 of the Rehabilitation Act of 1973, Pub. L. No. 93-112, as amended in 1974, Pub. L. No. 93-516. Extensive Section 504 regulations were promulgated in 1977, 42 Fed. Reg. 22676 (May 4, 1977) (codified at 45 C.F.R. Part 84). Neither the statute nor the legislative and regulatory history evidence any intent to apply Section 504 to individual treatment decisions involving impaired newborn infants.

21. *Initial Notice.* On May 18, 1982, Defendant issued a "notice" to health care providers "to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973." 47 Fed. Reg. 26027 (June 16, 1982) [hereinafter "Notice"]. The Notice stated that Section 504 made it unlawful for hospitals receiving Federal financial assistance to withhold from handicapped infants nutritional sustenance or medical or surgical treatment if required to correct a life-threatening condition. That Notice has not been explicitly rescinded or modified.

22. *Interim Final Rule.* On March 7, 1983, HHS promulgated, with only 15 days' notice, an "interim final rule" based on Section 504 concerning nondiscrimination on the basis of handicap. 48 Fed. Reg. 9630 (March 7, 1983). The rule required all hospitals which receive Federal financial assistance to post conspicuously in each delivery ward, maternity ward, pediatric ward, nursery, and intensive care nursery a notice stating that "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS . . . IS PROHIBITED BY FEDERAL LAW." The notice advised further that "[*a*]*ny person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:* Handicapped Infant Hotline. . . ." Telephone complaints received via the 24-hour, toll-free "hotline" were to be investigated and pursued in most cases by state child protective agencies. Regardless of actions by state agencies, the interim final rule authorized HHS: (a) to conduct immediate investiga-

tions, and (b) to make immediate referrals to the Department of Justice "for such legal action as may be necessary to save the life of a handicapped child...." When deemed necessary by an unidentified "responsible Department official," access to the facility itself and to the "pertinent records" would have had to be provided even outside of normal business hours.

23. *Invalidation of Interim Final Rule.* On April 14, 1983, the United States District Court for the District of Columbia declared the interim final rule invalid due to Defendant's violations of the Administrative Procedure Act. *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395 (D.D.C. 1983).

24. *HHS Enforcement Activities.* The ruling by the United States District Court for the District of Columbia did not enjoin HHS investigations and other enforcement activities undertaken pursuant to Section 504 with respect to treatment involving impaired newborn infants. Many complaints and reports received by HHS were in response to the May 18, 1982 Notice, which was also not affected by the District Court's decision. As of December 1, 1983, HHS' Office for Civil Rights had investigated, was investigating or had under consideration 49 complaints relating to treatment decisions involving impaired newborns. None of these actions had resulted in a finding of discriminatory withholding of treatment. A number of investigations or other enforcement actions undertaken by HHS before promulgation of the Final Regulation are still pending.

25. *Proposed Rule.* On July 5, 1983, HHS issued a proposed rule. The proposed rule still required establishment of a 24-hour "hotline" in hospitals and the posting of signs warning that withholding certain treatment from impaired newborn infants violated Section 504. State child protective agencies were required, under the proposal, to develop written rules and investigation procedures for handling "suspected cases of medical neglect of handicapped infants," although, as was the case with the invalidated interim final rule, it was contemplated that HHS itself "would closely monitor all investigation and enforcement activity taken pursuant to complaints."

26. *Final Regulation.* On January 12, 1984, HHS promulgated the Final Regulation which became effective on February 13, 1984 and which is challenged in this action. In most material respects, it is the same as or similar to the Interim Final Rule and to the Proposed Rule. *See* ¶¶ 29-33, *infra.*

27. Plaintiffs have exhausted all available administrative remedies which could provide the relief sought by this action.

28. *Second Circuit Decision.* On February 23, 1984, the United States Court of Appeals for the Second Circuit affirmed a decision by the United States District Court for the Eastern District of New York which refused to grant HHS access to medical records of an impaired newborn infant whose parents had decided not to authorize certain surgery. *United States* v. *University Hospital*, No. 83-6343 (2nd Cir. February 23, 1984). Defendant had sought the records in the fall of 1983, after the interim final rule was voided and before promulgation of the Final Regulation. In its opinion, the Court of Appeals held broadly that Section 504 did not apply to "treatment decisions involving defective newborn infants."

The Final Regulation: Provisions, Procedures and "Standards"

29. The Final Regulation has four mandatory provisions.

30. *Notice.* Section 84.55(b) requires each recipient health care provider that provides health services to infants in programs or activities receiving Federal financial assistance to post a notice, where nurses and other health care professionals will see it, which states, in part, that Section 504 prohibits discrimination on the basis of handicap and that under Section 504:

> nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

The required notice must include telephone numbers for a hospital contact point, the appropriate state child protective agency and a 24-hour a day HHS hotline where any person may call "to report suspected non-compliance" with the pre-

viously stated dictate of Section 504. There are no requirements that the person lodging a report have medical background or knowledge or have any direct personal knowledge of the particular course of treatment.

31. *State Agencies.* Section 84.55(c) provides that state child protective agencies which are recipients of Federal funds shall, within 60 days of the effective date of the Final Regulation, establish and maintain in written form "methods of administration and procedures to assure that the agency utilizes its full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants." All states have such agencies. These "methods and procedures" include a requirement that physicians and other health care providers must report on a timely basis to the state agency "circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants." These state agencies must also establish procedures for receiving such reports, reviewing them, conducting on-site investigations and "seeking a timely court order to compel the provision of necessary nourishment and medical treatment." The state agencies must also establish procedures for informing HHS of each report of "suspected medical neglect," the steps taken to investigate such report and the state agency's final disposition of such report. Altnough the state agencies have 60 days in which to establish such written procedures, they have a present obligation to handle all "reports" of "medical neglect" from anonymous individuals, health professionals or HHS regarding treatment of impaired newborns, and health professionals have a present obligation to make such reports.

32. *HHS Investigations.* Section 84.55(d) authorizes HHS to have a 24-hour a day access to pertinent medical records and facilities. HHS may conduct an on-site investigation any time a responsible departmental official determines that immediate action is necessary to protect the life or health of an infant.

33. *Expedited Compliance Actions.* Section 84.55(e) authorizes HHS to take expedited action against recipients of Federal financial assistance to effect compliance with Section 504, including action by the Department of Justice, without providing notice to such recipients, if, in the judgment of the

responsible Department official, such action is necessary to protect the life or health of an infant.

34. None of the mandatory provisions of the Final Regulation have a basis in fact or are designed to meet a documented problem. HHS did not consider all the relevant factors before intruding into the sensitive area of individual treatment decisions involving impaired newborns. The Final Regulation is also devoid of any comprehensible standards or procedural safeguards regarding, *inter alia:* who may file reports; when it is appropriate or required to file such reports; what sort of evidence triggers an investigation; what qualifications shall be possessed by the person who decides to investigate; how investigations shall be carried out; what shall be investigated; who shall determine if proceedings shall be brought against parents; what standards shall govern such a decision; what standards shall govern a Federal decision that a state agency did not investigate properly or did not appropriately proceed against a parent; what standards shall govern a Federal decision that a recipient or physician or other provider did not properly report an instance of "known or suspected" medical neglect.

Injury

35. The allegations of paragraph 1 to paragraph 34 are incorporated by reference herein and realleged by reference.

36. Plaintiff physicians and medical and other health care organizations have suffered, are presently suffering and are imminently threatened with irreparable injuries as a result of HHS' Final Regulations and its unlawful application of Section 504 to treatment involving impaired newborn infants.

37. These past, present or threatened irreparable injuries are suffered directly by Plaintiff physicians and medical and other health care organizations; these injuries are the direct result of Defendant's interpretation of, and actions under, Section 504 with respect to the regulation of treatment involving impaired newborns; and the injuries will be redressed, or the threat of injury will be removed, by a favorable decision in this action. Plaintiffs' affidavits, which are attached to the memorandum in support of Plaintiff's motion for preliminary injunction, are incorporated by reference herein.

38. Parents, expectant parents and parents of impaired newborns generally, who have ultimate authority to act in the best interests of their children, and whose interests are appropriately asserted in this action by the physician Plaintiffs, are injured as a result of HHS' application of Section 504 to treatment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia:*

a. They have been, are or are threatened with being, the subject of "reports" lodged with hospitals, state authorities or HHS by third parties who have no medical training or medical knowledge, who have no direct personal knowledge of the facts of treatment decisions made by parents involving their impaired newborns and who do not realize that, contrary to the required notice provision of the Final Regulation, Section 504 does not apply to treatment decisions about impaired newborn infants;

b. They have been or are the subject of intrusive Federal or Federally compelled state investigations into their decisions involving the treatment of their impaired newborns, including invasion of their confidential relationship with their child's physicians and with other treating health professionals; or they are threatened with such investigations; and such intrusive investigations have occurred, are occurring or will occur when parents are in the middle of an anguishing decision-making process on behalf of their children;

c. They have suffered, are suffering or are threatened with suffering violations of their confidential relationship with the impaired infants' physicians and with other treating health professionals who are by Federal law required to report to state authorities cases of "known" or "suspected" parental neglect under vague and uncertain federal "neglect" standards;

d. They have been, are or will be at risk of Federally coerced actions by state authorities which challenge their fitness to make treatment decisions involving their impaired newborns;

e. They have suffered or are suffering distress, anxiety and fear at the widely publicized application by HHS of Section 504 to parents' individual treatment decisions on behalf

of their impaired newborn infants; at HHS's failure to define unlawful discrimination and neglect in a way that they or their physicians can understand; at the uncertainty which HHS's action has created for their confidential relationship with health professionals and for their confidence that health professionals are acting in the interest of their child; and this distress, anxiety or fear intrudes on their private decision-making and thus harms their infant children; and

f. They have suffered, are suffering or are threatened with suffering diminished quality of medical care for their newborn infants.

39. Physician Plaintiffs Hubert A. Ritter, Peter A. M. Auld, Rita Gilman Harper and Roy Howard Petrie are injured as a result of HHS' application of Section 504 to treatment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia:*

a. They are being subjected to legal duties regarding medical decisions under Federal regulatory standards—*e.g.*, "solely qualified," "discrimination," "medically beneficial treatment" and "medical neglect"—that have no clearly accepted or understood meaning with respect to the treatment of newborns with serious mental or physical impairments given the present state of medical knowledge;

b. They are being subjected to potentially inconsistent legal duties because "discrimination" and "medical neglect" as used in the May 18, 1982 Notice and in the Final Regulation are not susceptible of definition given the state of present medical knowledge and have a unique Federal meaning that is at odds with, or not yet recognized under, state law definitions which create physicians' legal obligations;

c. They have been, are or will be required to violate their confidential relationship with the parents of a seriously newborn child by responding to investigations of "reports" of medical neglect filed by third parties who lack medical training or knowledge or who lack direct personal knowledge of the treatment decisions made by parents in consultation with physicians;

d. They have been, are or will be injured in their ability to exercise professional medical judgment in the best interests of their patients;

e. They are threatened with being required to violate their confidential relationship with the parents of an impaired newborn child by the Federally imposed mandate that they "report" instances of "medical neglect" by parents when the standards governing such a duty is vague or at odds with medical practice and knowledge; and

f. Their impaired newborn patients, and the parents acting in the best interests of those patients, suffer injuries like those described in paragraph 38, incorporated by reference herein, and the physician Plaintiffs seek to protect such patients and parents from such injuries.

40. Plaintiff American Medical Association ("AMA") is injured, in its capacity of representative of 256,000 American physicians, as a result of HHS' application of Section 504 to treatment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia:*

a. The injuries suffered by the individual named physicians are typical of the injuries which the AMA's relevant member physicians across the nation will suffer as a result of HHS' policies, actions and regulations which have nationwide application and effect, and paragraph 39 is incorporated by reference herein and realleged;

b. The physician interests implicated by HHS' action are germane to the AMA's purposes which are, *inter alia*, to improve the quality of care to patients, including impaired newborn infants, and to protect the confidentiality of medical records and the doctor-patient relationship; and

c. The injuries suffered by the individual named physicians are illustrative of the injuries that all affected members of the AMA will suffer nationwide and the relief requested does not require participation of individual physicians in this action.

41. Plaintiff American College of Obstetricians and Gynecologists ("ACOG") is injured, in its capacity as representative of 24,000 American obstetricians and gynecologists, as a result of HHS' application of Section 504 to treatment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia*:

a. The injuries suffered by the Physician Plaintiff Peter A. M. Auld are typical of the injuries which ACOG's rele-

vant member physicians across the nation will suffer as a result of HHS' policies, actions and regulations which have nationwide application and effect, and paragraph 39 is incorporated by reference herein and realleged;

b. The physician interests implicated by HHS's action are germane to ACOG's purposes, which are, *inter alia*, to improve the quality of care to patients, including impaired newborn infants, and to protect the confidentiality of medical records and the doctor-patient relationship; and

c. The injuries suffered by the individual named physician is illustrative of the injuries that all affected members of ACOG will suffer nationwide and the relief requested does not require participation of individual physicians in this action.

42. Plaintiff American Academy of Family Physicians ("AAFP") is injured, in its capacity as representative of 56,000 American family physicians and medical students, as a result of HHS' application of Section 504 to treatment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia:*

a. The injuries suffered by the individual named physicians are typical of the injuries which AAFP's relevant member physicians across the nation will suffer as a result of HHS' policies, actions and regulations which have nationwide application and effect, and paragraph 39 is incorporated by reference herein and realleged;

b. The physician interests implicated by HHS' action are germane to AAFP's purpose which are, *inter alia*, to promote excellence in health care and in the delivery and care of newborn infants; and

c. The injuries suffered by the individual named physicians are illustrative of the injuries that all affected members of AAFP will suffer nationwide and the relief requested does not require participation of individual physicians in this action.

43. Plaintiffs American Hospital Association ("AHA"), Hospital Association of New York State ("HANYS") and Association of American Medical Colleges ("AAMC") are injured as a result of HHS' application of Section 504 to treat-

ment decisions involving impaired newborn infants and as a result of the Final Regulation because, *inter alia:*

a. Their member hospitals are required to post a notice which is inaccurate because Section 504 does not apply to treatment involving impaired newborn infants and which describes legal duties for their employees and medical staffs regarding medical decisions that have no accepted or understood meaning with respect to treatment involving impaired newborns given the present state of medical practice and knowledge;

b. The required notice, which is widely known by parents of newborns because of national publicity and which is likely to be brought to their attention within a hospital, will cause fright and anxiety in such parents and will lessen their confidence in hospitals and in the practice of medicine within hospitals;

c. Staff and employees within their member hospitals have been or are required to violate confidentiality requirements by responding to "reports" of medical neglect filed by third parties who lack medical training or knowledge or who lack direct personal knowledge of the treatment decisions made by parents in consultation with physicians;

d. Their member hospitals are required to force their staffs to report "suspected" instances of parental neglect to state agencies in violation of confidentiality requirements; and

e. Their member hospitals will be subjected to Federal investigations and compliance actions which are triggered without appropriate standards or due process safeguards.

COUNT I: Violation of Statutory Mandates

44. The allegations of paragraphs 1 through 43 are incorporated herein and realleged by reference.

45. Defendant's Final Regulation, her implementation of the Regulation and her other investigation and enforcement activities under Section 504 with respect to treatment involving newborn infants are unlawful as beyond the statutory authority of Section 504 because, *inter alia:*

a. Congress did not intend Section 504 to regulate treatment of impaired newborn infants;

b. Congress did not intend Section 504 to regulate directly or indirectly parental autonomy or treatment decision-making involving their impaired newborn infants;

c. Congress did not intend that newborns with serious mental or physical impairments be an "otherwise qualified" handicapped individual who may thus suffer "discrimination" in treatment decisions within the meaning of Section 504;

d. Congress did not intend that hospitals and physicians would have to undertake affirmative obligations with respect to impaired newborn infants; and

e. Congress did not intend that the Medicare and Medicaid programs would constitute Federal financial assistance to hospitals for purposes of triggering application of Section 504 to treatment decisions involving impaired newborn children; nor did Congress intend that, if Medicare and Medicaid are such assistance, this fact triggers application of Section 504 to all treatment decisions made by recipients' employees or staff in recipients' activities which do not receive Federal assistance.

COUNT II: Violation of the Administrative Procedure Act

46. The allegations of paragraphs 1 to 45 are incorporated herein and realleged by reference.

47. In promulgating the Final Regulation, Defendant has acted in an arbitrary and capricious manner, abused her discretion, taken actions otherwise not in accordance with the law and thus violated Section 10(e) of the Administrative Procedure Act, 5 U.S.C. § 706(2)(A), because, *inter alia:*

a. Defendant failed to demonstrate any factual basis for the Final Regulation because there are no instances cited where "erroneous" treatment decisions were made by parents *and* where hospitals or physicians did not seek protective orders from state agencies and because there is no evidence of actual cases where hospitals and physicians act differently with respect to handicapped and non-handicapped children in terms of reporting cases of abuse and neglect to state child protective agencies;

b. Defendant failed to describe or to survey present procedures employed by hospitals and other health care providers to protect impaired newborns if parents are deemed by

such hospitals and providers to be incapable of making decisions or to explain why such procedures are inadequate;

c. Defendant failed adequately to address the harmful effects of the regulation on impaired newborn infants themselves, ignoring probative evidence that the investigations mandated by the regulation have disrupted and will disrupt on-going treatment of impaired infants;

d. Defendant similarly failed to take adequate account of the far-reaching impact of the Final Regulation on parents, physicians and hospitals;

e. Defendant failed systematically to survey state child neglect law, to report any findings of such survey and to analyze the possible contradictions or inconsistencies between the Final Regulation's definition of "discrimination" and "medical neglect" and the standards for child neglect under state laws, and the effect on recipients and providers of these contradictions or inconsistencies;

f. Defendant failed to respond to significant comments and proposals made during the rulemaking proceeding; and

g. Defendant failed to show that the specific regulatory approach chosen bears a rational relationship to the objectives adopted by Defendant.

COUNT III: Violation of Privacy Rights Guaranteed by the Constitution and by Statute

48. The allegations of paragraphs 1 through 47 are incorporated herein and realleged by reference.

49. Defendant's Final Regulation, her implementation of the Regulation and her investigations and other enforcement activities under Section 504 with respect to medical decisions involving treatment of impaired newborn infants are unlawful as violative of parents' constitutional right of privacy to make fundamental personal decisions affecting family and children free from government interference because, *inter alia*:

a. Defendant's actions massively intrude on parents' right to make autonomous treatment decisions on behalf of their infant children;

b. Defendant's actions massively intrude on the parents' corollary right in making such decisions to consult fully and freely with physicians and to have physicians' ability to make

their best medical judgments be unimpeded by governmental interference; and

c. Defendant's actions injuring parents' constitutional rights are not justified by the requisite Federal interest.

50. Defendant's Final Regulation, her implementation of the Regulation and her investigations and other enforcement activities under Section 504 with respect to treatment involving impaired newborns are unlawful as violative of parents' constitutional and statutory rights of privacy to have personal matters free from disclosure because, *inter alia:*

a. Investigations into parents' sensitive personal and family medical matters and decisions about treatment have been or will be triggered without any standards and without adequate procedural safeguards;

b. Physicians and other health professionals have been or will be forced to violate ethical and statutory dictates in responding to such inappropriate investigations and to divulge confidential information about parents and their impaired newborn child; and

c. Hospitals and their employees have been or will be forced to violate ethical and statutory dictates in providing sensitive and confidential medical records containing information about parents and their impaired newborn child in response to such inappropriate investigations.

PRAYER FOR RELIEF

Plaintiffs respectfully request the following relief:

1. Defendant's Final Regulation on "Procedures and Guidelines Relating to Health Care for Handicapped Infants" should be declared invalid as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; as violating the requirements of the Administrative Procedure Act, 5 U.S.C. § 551 *et seq.*; as violating constitutional and statutory rights of privacy; and thus as having no further force and effect.

2. Defendant, her officers, agents, employees and attorneys should be permanently enjoined from any further implementation of the Final Regulation with respect to any program or activity receiving Federal financial assistance in any state, as defined in 29 U.S.C. § 706(14);

3. Defendant's other actions to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions, should be declared unlawful as exceeding the scope of Defendant's authority under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; as violating constitutional and statutory rights of privacy; as thus having no further force and effect; and Defendant, her officers, agents, employees and attorneys should be permanently enjoined from continuing such actions with respect to any program or activity receiving Federal financial assistance in any state as defined in 29 U.S.C. § 704(14); and

4. Plaintiffs should be awarded the costs of this action, including attorney's fees, and such other relief as may be just and equitable under the circumstances.

Respectfully submitted,

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Attorneys for Plaintiffs

Dated: MARCH 12, 1984

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638 (CLB)

AMERICAN HOSPITAL ASSOCIATION
ON BEHALF OF ITS MEMBER HOSPITALS,

HOSPITAL ASSOCIATION OF NEW YORK STATE,
ON BEHALF OF ITS MEMBER HOSPITALS,

AND

STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER, PLAINTIFFS,

v.

MARGARET M. HECKLER, SECRETARY,
UNITED STATES DEPARTMENT OF HEALTH
AND HUMAN SERVICES,
DEFENDANT.

AMENDED COMPLAINT

Pursuant to Rule 15(a) of the Federal Rules of Civil Procedure, the plaintiffs amend their complaint in this action.

Jurisdiction and Venue

1. This court has subject matter jurisdiction pursuant to 26 U.S.C. §§ 1331, 2201 and 2202, and 5 U.S.C. § 706. Venue is proper in this district under 28 U.S.C. § 1319(e).

Parties

2. Plaintiff American Hospital Association ("AHA") is an association of hospitals within the United States with approximately 6,000 member hospitals, the vast majority of which are directly and immediately affected by the federal regulation at issue in this case.

3. Plaintiff Hospital Association of New York State ("HANYS") is the association of hospitals within New York State.

4. Strong Memorial Hospital of the University of Rochester is a hospital located in Rochester, New York which provides care to infants including seriously-ill infants.

5. Defendant Margaret M. Heckler is the duly appointed Secretary ("the Secretary") of the United States Department of Health and Human Services ("DHHS") and is the federal official responsible for the administration of the regulation at issue in this action.

Statement of the Case

6. On June 16, 1982, the Office of Civil Rights of the DHHS caused to be published in the Federal Register, on behalf of the Secretary, a notice which stated that DHHS regulations regarding discrimination against the handicapped in programs receiving federal financial assistance (codified at 45 C.F.R. § 84) were applicable to the medical treatment of seriously-ill infants.

7. On March 7, 1983, without first providing for comment by interested parties, and with no evidence of any problem calling for the initiation of the regulatory process, the Secretary promulgated an interim final rule, 48 Fed. Reg. 9630, which became effective on March 22, 1983. The sole purported statutory authority for the rule was Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

8. The interim final rule erroneously purported to interpret Section 504 by extending its reach to infants with birth defects. Thus, the Secretary asserted that "discriminatory failure to feed and care for handicapped infants in [a hospital] is prohibited by federal law." Hospitals subject to this requirement were required to post notices to this effect in conspicuous places in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery. In addition, the notice was required to indicate that a toll-free hotline, available 24 hours a day, would be provided to all persons who wish to make complaints, including anonymous complaints. Moreover, the preamble to the rule made it clear that the Secretary could conduct immediate investigations and make immediate referrals to the Department of Justice for such legal action as might be deemed necessary. Such action could be taken regardless

of the wishes of an infant's parents or other legal guardians, and regardless of the views of appropriate state law enforcement agencies or courts.

9. The interim final regulation promulgated on March 7, 1983, was intended by the Secretary to be applicable to every hospital which accepts Medicare, 42 U.S.C. §§ 1395, *et seq.*, or Medicaid reimbursement, 42 U.S.C. §§ 1396, *et seq.*, or which has received Hill-Burton assistance pursuant to 42 U.S.C. §§ 291, *et seq.*

10. The vast majority of the member hospitals of the AHA and HANYS receive Medicare reimbursement. In addition, a large number of member hospitals of both receive Medicaid reimbursement. Finally, more than 3,500 hospitals have received Hill-Burton assistance between 1947 and 1974.

11. On April 6, 1983, the plaintiffs filed the original complaint in this case, seeking a judgment declaring the interim final regulation invalid and restraining or enjoining the enforcement of that regulation.

12. On April 6, 1983, this Court temporarily restrained and enjoined defendant from enforcing the interim final rule "solely to the extent it purports to require the posting of notices upon the premises of voluntary or municipal hospitals within New York State...." The Court also scheduled a hearing for April 18, 1983, on plaintiffs' application for a preliminary injunction.

13. On April 14, 1983, the United States District Court for the District of Columbia, in a parallel case, struck down the interim final rule for failing to satisfy the requirements of the Administrative Procedure Act, 5 U.S.C. §§ 551, *et seq.* (1982). *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 400-401 (D.D.C. 1983).

14. The court in *American Academy* also ordered defendant to "place an order in the Federal Register advising that said interim final rule has been declared invalid and has no further force and effect, ..." and defendant did so declare and publish on April 25, 1983. 48 Fed. Reg. 17588.

15. In view of the invalidation of the interim final rule in the District of Columbia, the hearing scheduled by this Court for April 18, 1983 was cancelled, and defendant never

has filed or served on the plaintiffs an answer to the complaint herein.

16. On July 5, 1983, defendant proposed a somewhat revised rule (48 Fed. Reg. 30846), which itself was slightly modified when, on January 12, 1984, DHHS issued its "final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants" 45 C.F.R. § 84.55 (49 Fed. Reg. 1622). The sole purported authority for both the revised and final rule, like that for the interim final rule, is Section 504 of the Rehabilitation Act, 29 U.S.C. § 794.

17. The final rule, 45 C.F.R. § 84.55, as set forth at 49 Fed. Reg. 1622, *et seq.*, provides, *inter alia*, that:

> a. hospitals shall post a notice stating that Section 504 of the Rehabilitation Act requires that "nourishment and medically beneficial treatment . . . not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments" [§ 84.55(b), 49 Fed. Reg. at 1651];
>
> b. said notice shall include a telephone number which may be called to "report suspected noncompliance" and shall state that the "identity of callers will be held confidential" [*id.*];
>
> c. state child protective services agencies must implement procedures for "immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports," for seeking court orders "to compel the provision of necessary nourishment and medical treatment," as well as for timely notification to DHHS of such reports and the agencies' investigation thereof [§ 84.55(c)(iii), (iv) and (v), 49 Fed. Reg. at 1651];
>
> d. hospitals must grant DHHS officials "immediate access" to "pertinent records and facilities" when the responsible DHHS official considers such access "necessary to protect the life or health of a handicapped individual" [§ 84.55(a), 49 Fed. Reg. at 1652]; and
>
> e. DHHS may, without prior notice, take expedited action to affect compliance where "necessary to protect the life or health of a handicapped individual" [§ 84.55(e), 49 Fed. Reg. at 1652].

18. The final rule therefore duplicates most of the essential aspects of the initial rule that was struck down and perpetuates the undesirable effects of that initial rule.

19. DHHS' final rule, which became effective on February 13, 1984, subjects plaintiff Strong Memorial Hospital and the many other hospital members of plaintiff associations to the requirements and procedures set forth in that rule, including those requirements and procedures described in paragraph 17, *supra*.

20. On February 23, 1984, the United States Court of Appeals for the Second Circuit ruled on the issue of whether Section 504 authorized DHHS to obtain access to a hospital's medical records concerning the treatment of an infant with serious birth defects. In answering that question with a definitive "no" the Court held that "congress never intended that Section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants . . ., and that DHHS lacks authority for "the type of investigation that has precipitated this lawsuit." *United States* v. *University Hospital*, No. 83-6343 (2d Cir. Feb. 23, 1984) (slip op. at 1938-39).

21. The Court of Appeals likewise found no evidence that congress, in enacting Section 504, "intended to repeal" its "consistent . . . policy against involvement of federal personnel in medical treatment decisions, . . ." *Id.*, slip op. at 1936-37. In so holding, the Court recognized that any intervention by the government with the goal of applying Section 504 to infants with birth defects would, necessarily, involve federal personnel in evaluating, influencing and altering medical treatment decisions.

Injury

22. By its own terms, the DHHS rule is final. There is no further avenue for administrative relief, and the rule creates affirmative present obligations for the member hospitals of the plaintiff associations and for plaintiff Strong Memorial Hospital.

23. This final rule is applicable nationwide and the injury suffered by plaintiff Strong Memorial Hospital is typical of the injury suffered by the other member hospitals of the plaintiff associations.

24. If the Secretary's final rule is not held invalid and its enforcement is not enjoined, the member hospitals of the plaintiff associations and plaintiff Strong Memorial Hospital will continue to be irreparably injured in that:

a. no monetary measure can be made of the extent of the injury that plaintiffs are suffering because of the unlawful rule at issue, thus leaving plaintiffs with no adequate remedy at law;

b. the clear decision of the Court of Appeals in *University Hospital* will be flouted;

c. hospitals are required to post a notice which inaccurately states that federal law imposes upon hospital staff certain legal duties and obligations with regard to medical treatment decisions involving seriously-ill infants;

d. DHHS investigations and demand for access to patient records undertaken pursuant to DHHS' regulations, and often conducted by individuals lacking adequate knowledge or training, have been, and may be expected to continue to be, disruptive of normal and important hospital activities, and heedless of the confidentiality of patient records and the prohibitions against permitting unconsented examination of patients. See affidavits of Paul M. Rosenberg and J. Alexander McMahon, submitted with plaintiffs' original complaint herein, and the affidavit of Richard L. Epstein submitted herewith.

e. for the same reasons, the on-site investigations by state child protective agencies, compelled by a federal regulation that contains no substantive or procedural standards or limitations, are likely to be equally disruptive;

f. federally mandated suits by state child protective agencies to "compel the provision of necessary nourishment and medical treatment" will generate widespread publicity and will raise doubts and fears concerning the nature and quality of care provided by hospitals named as defendants (*see, e.g.*, Rosenberg affidavit);

g. the doubts and fears engendered by such investigations and lawsuits have induced parents to withdraw their children as patients, and may be expected in the future to induce individuals to refrain from entering or remaining in subject hospitals;

h. the conduct of the government under the rule necessarily intrudes into and interferes with parental decision-making;

i. the conduct of the government under the rule necessarily interferes with the formation and communication of accurate medical judgments and is disruptive and inhibitory of the delivery of services by hospitals and physicians throughout the nation.

COUNT I

(Violation of Section 504 of the Rehabilitation Act of 1973)

25. Plaintiffs reallege the allegations of paragraphs 1-23, *supra*, which are incorporated by reference as if set forth herein in full.

26. Because the final rule at issue here finds its only source of purported authority in Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, it has been rendered unlawful on its face by the Second Circuit's decision in *United States* v. *University Hospital*, *supra*, in that:

a. Congress did not intend that Section 504 would apply to treatment decisions involving infants with birth defects; and

b. Congress did not intend that Section 504 repeal the longstanding congressional policy against the involvement of federal personnel in medical treatment decisions, and any activity by the federal government under the banner of Section 504 necessarily would involve the federal government in such prohibited activity.

27. The final rule is also unlawful because the federal government has no authority under Section 504 to interfere with the rights of parents to choose among treatment alternatives for their children.

28. The final rule is further unlawful because its coverage is premised upon the mere receipt by hospitals of Medicare and Medicaid reimbursements, which do not constitute federal financial assistance within the congressional intendment of Section 504. *See, Grove City College* v. *Bell*, 52 U.S.L.W. 4283 (U.S. Feb. 28, 1984).

COUNT II

(Violation of the Administrative Procedure Act)

29. Plaintiffs reallege the allegations of paragraphs 1-27, *supra*, which are incorporated by reference as if set forth herein in full.

30. In view of the Second Circuit's decision in *United States* v. *University Hospital*, *supra*, and the matters set forth in paragraphs 25-27, *supra*, the final rule must, under the requirements of the Administrative Procedure Act, 5 U.S.C. § 706(2)(C), be held "unlawful and set aside " because it is "in excess of statutory jurisdiction, authority, . . . or short of statutory right."

31. The final rule also must be set aside under 5 U.S.C. § 706(2)(A) because in promulgating and implementing it, the defendant has acted arbitrarily and capriciously, abused her discretion and otherwise has violated the law.

RELIEF REQUESTED

A. Declaratory Judgment

32. The continuation of the rule in the wake of the Second Circuit's *University Hospital* decision, which clearly mandates the invalidation of the rule, presents "a substantial controversy, between parties having adverse legal interests, of sufficient immediacy to warrant the issuance of a declaratory judgment." *Maryland Casualty Co.* v. *Pacific Co.*, 312 U.S. 270, 273 (1940); *see Super Tire Engineering Co.* v. *McCorkle*, 416 U.S. 115, 122 (1974).

33. For the foregoing reasons, this Court should enter a judgment pursuant to 28 U.S.C. § 2201 and 2202, declaring the invalidity of DHHS' final rule, granting the relief sought for by plaintiff embodied in 45 C.F.R. § 84.55, 49 Fed. Reg. 1622, *et seq.* (Jan. 12, 1984).

B. Injunctive Relief

34. As set forth in paragraphs 21-23, *supra*, which are incorporated by reference herein, plaintiffs are suffering irreparable injury of a direct and immediate nature because of the requirements and expected enforcement of the final rule.

35. In view of the Second Circuit's *University Hospital* decision, holding that DHHS has no authority under Section

504 to intervene or act in regard to the treatment of infants with birth defects, and in view of the fact that the final rule has as its only basis the purported authority of Section 504, plaintiffs have a manifestly substantial likelihood of success on the merits of this lawsuit.

36. The hardships inherent in the existence and enforcement of the final rule tip decidedly towards plaintiffs; the Secretary can suffer no cognizable hardship if the rule she seeks to enforce is unlawful.

37. Plaintiffs satisfy all requirements for the issuance of injunctive relief. *See, e.g., Standard & Poor's Corporation, Inc.* v. *Commodity Exchange, Inc.*, 683 F.2d 704, 707-708 (2d Cir. 1982).

38. For the foregoing reasons this Court should issue a preliminary and permanent injunction prohibiting the defendant from enforcing her final rule embodied in 45 C.F.R. § 84.55, 49 Fed. Reg. 1622, *et seq.* (Jan. 12, 1984), and prohibiting defendant from otherwise acting pursuant to the claimed authority of Section 504 of the Rehabilitation Act of 1973 in regard to the medical treatment of infants with birth defects.

WHEREFORE, plaintiffs pray that this Court issue the declaratory judgment and injunctive relief sought, and such other and further relief, including the costs and attorneys' fees incurred by plaintiffs in this action, as this Court deems appropriate.

Respectfully submitted,
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/s/ _____
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/s/ _____
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Attorneys for Plaintiffs

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

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83 Civ. 2638 (CLB)

AMERICAN HOSPITAL ASSOCIATION,
ON BEHALF OF ITS MEMBER HOSPITALS,

HOSPITAL ASSOCIATION OF NEW YORK STATE,
ON BEHALF OF ITS MEMBER HOSPITALS,

AND

STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER, PLAINTIFFS,

v.

MARGARET M. HECKLER, SECRETARY, UNITED STATES
DEPARTMENT OF HEALTH AND HUMAN SERVICES,
DEFENDANT.

MOTION FOR
PRELIMINARY INJUNCTION

Pursuant to Rule 65 of the Federal Rules of Civil Procedure, the plaintiffs American Hospital Association ("AHA"), Hospital Association of New York State ("HANYS"), and the Strong Memorial Hospital of the University of Rochester ("Memorial Hospital"), upon their amended complaint, and the affidavits previously filed in this action, move this honorable Court to issue a preliminary injunction suspending and restraining the operation, enforcement, or execution of the final rule of the Department of Health and Human Services pertaining to medical treatment of infants with birth defects, 45 C.F.R. § 84.55, 49 Fed. Reg. 1622, *et seq* (Jan. 12, 1984).

The grounds of this motion, as more fully set forth in the amended complaint and in the annexed exhibits and the previously-filed affidavits of J. Alexander McMahon and Paul M. Rosenberg, and in the affidavit of Richard L. Epstein, are that:

a. the final rule is invalid because, as the United States Court of Appeals for the Second Circuit has held, Section

504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, the sole purported authority for the final rule, does not authorize governmental involvement in medical treatment decisions concerning seriously-ill infants. *United States* v. *University Hospital*, No. 83-6343 (2d Cir. Feb. 23, 1984);

b. the final rule also is unlawful under the Administrative Procedure Act, 5 U.S.C. § 706(2)(A) and (C);

c. DHHS, unless enjoined, will continue to enforce the rule;

d. the rule and its enforcement are causing and will cause immediate and irreparable injury to the plaintiffs;

e. plaintiffs have no adequate remedy at law;

f. plaintiffs have demonstrated a substantial likelihood of success on the merits; and

g. the balance of hardships decidedly shifts towards the plaintiffs.

WHEREFORE, plaintiffs respectfully submit that this Court should enter a preliminary injunction rendering unenforceable defendants' final rule embodied in 45 C.F.R. § 84.55.

Respectfully submitted,
Epstein Becker Borsody & Green, P.C.

/s/ _____

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(212) 370-9800

/s/ _____

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Attorneys for Plaintiffs

BEST AVAILABLE COPY

APPENDIX G

UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF NEW YORK

Civil Action No. 83 Civ. 2638 CLB

AMERICAN HOSPITAL ASSOCIATION,
ON BEHALF OF ITS MEMBER HOSPITALS,
HOSPITAL ASSOCIATION OF NEW YORK STATE,
ON BEHALF OF ITS MEMBER HOSPITALS,
AND
THE STRONG MEMORIAL HOSPITAL OF THE
UNIVERSITY OF ROCHESTER,
PLAINTIFFS,
v.
MARGARET M. HECKLER, SECRETARY,
UNITED STATES DEPARTMENT OF HEALTH
AND HUMAN SERVICES, DEFENDANT.

AFFIDAVIT

City of Washington)
) :ss
District of Columbia)

Richard L. Epstein deposes and says:

1. I am Senior Vice President of the American Hospital Association ("AHA"). The membership of the AHA comprises approximately 6,000 of the nation's 7,000 hospitals. The AHA serves its member hospitals in various ways including providing information and educational materials, and conducting seminars concerning developments in techniques and procedures for enhancing quality patient care, employee safety and related health-delivery matters. The AHA also provides information to its member hospitals with regard to the promulgation and content of federal regulations and statutes applicable to the health field.

2. I have read and am familiar with the contents of the affidavits of J. Alexander McMahon and Paul M. Rosenberg, filed with the original complaint in this case. I believe that

the relevant allegations of those affidavits continue to be true in regard to the final rule concerning medical treatment of seriously-ill infants promulgated by the Department of Health and Human Services ("DHHS") on January 12, 1984. (45 C.F.R. § 84.55, 49 Fed. Reg. 1622, *et seq.*)

3. This rule is of nationwide scope and application and, in my position, I am aware of and responsible for replying to numerous inquiries and expressions of concern from AHA member hospitals regarding the rule. The AHA is concerned with present and future irreparable harm to hospitals, physicians who practice in hospitals and the parents and patients who rely on hospitals, resulting from the implementation and projected enforcement of the final rule.

4. This final rule by its terms, deals substantially with medical treatment decisions concerning seriously ill infants, including infants with life-threatening disorders. The United States Court of Appeals for the Second Circuit has held that the sole purported statutory authority for the rule (Section 504 of the Rehabilitation Act of 1973) does not authorize the government to engage in the types of conduct contemplated by the rule. The final rule is contrary to law and sound public policy and is causing and will continue to cause irreparable harm to AHA's members and other hospitals, their personnel and medical staffs, and to the parents of infants who are treated in hospitals.

5. The final rule, which became effective on a nationwide basis on February 13, 1983, requires that hospitals receiving Medicare and Medicaid reimbursement post notices stating that Section 504 prohibits the withholding of "nourishment and medically beneficial treatment . . ." from handicapped infants solely on the basis of their present or anticipated impairments" and providing a confidential 24-hour telephone line for reporting "suspected noncompliance." The final rule further requires hospitals to grant DHHS officials "immediate access" to "pertinent records and facilities" when the responsible DHHS official considers such access "necessary to protect the life or health of a handicapped individual," and authorizes DHHS to take expedited action, without prior notice, to effect compliance where "necessary to protect the life or health of a handicapped individual." The final rule also re-

quires state child protective services agencies to implement procedures for "immediate review of reports of suspected unlawful medical neglect of handicapped infants and, where appropriate, on-site investigation of such reports," for seeking court orders "to compel the provision of necessary nourishment and medical treatment," as well as for timely notification to DHHS of such reports and the agencies' investigation thereof.

6. In its essential operative elements, particularly as to the notice-posting requirement, the "hotline" and the investigative proceedings, the rule is substantially the same as the Secretary's initial rule which was held unlawful. Moreover, the final rule perpetuates the harms occasioned by the initial rule.

7. Hospitals and their staffs are now being injured by the requirement that they post notices which erroneously state that Section 504 applies to medical treatment decisions involving seriously-ill infants. By their terms and locations, these notices imply that hospital staff has a duty to initiate governmental investigations without any objective criteria for the sufficiency of care or the exercise of medical judgment having been set forth. This situation is presently, and will remain, a source of potentially-severe disruption of the mission of care of AHA members and other hospitals.

8. Physicians and parents also are presently harmed by the inhibitory effect which the rule and its expected enforcement exerts upon their deliberations regarding the care to be provided to seriously ill infants. This undermines the discharge of hospitals' responsibilities to support the exercise of informed judgment by physicians and parents.

9. Hospitals will be irreparably harmed in the future by the enforcement of the final rule. DHHS' investigations and demands for access to patient records undertaken pursuant to DHHS' prior regulations and demands have been conducted by individuals lacking adequate knowledge or training, and have been disruptive of normal and important hospital activities and heedless of the confidentiality of patient records and the prohibitions against permitting unconsented examination of patients. DHHS investigations conducted pursuant to the final rule will be equally disruptive, as will

the on-site investigations by state child protective agencies, for the same reasons.

10. Hospitals also will be irreparably harmed by suits brought by the federal government and, pursuant to DHHS directives, by state child protective agencies, to compel specific courses of treatment, regardless of medical and parental decisions, or to compel access to patient records. Moreover, such investigations, under the rule, would be conducted without stated substantive or procedural safeguards or limitations. As has been the case in the past, suits and investigations generate widespread publicity and unwarranted anxiety concerning the nature and quality of care provided by hospitals named as defendants.

11. Physicians and other medical professionals will be irreparably harmed by the final rule by its mandated governmental intrusion into the process of medical treatment.

12. The final rule also inflicts irreparable harm upon parents of seriously-ill infants and the infants themselves. The AHA is informed that because of apprehensions raised by lawsuits and investigations, parents have withdrawn their infants as patients, and that in the future parents may be expected to refrain from permitting their children to enter or remain in the subject hospitals' care.

13. Inasmuch as the final rule is applicable on a nationwide basis to all hospitals that receive Medicare and Medicaid reimbursement, the present and future irreparable harm described herein also will be nationwide in scope, unless implementation and enforcement of the final rule are enjoined.

/s/ _____
RICHARD L. EPSTEIN
Senior Vice President
American Hospital Association

Subscribed to and sworn before me this 8th day of March 1984.

/s/ _____
Notary Public

My commission expires:
1/1/89

APPENDIX J

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

Civil Action No.

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS,

v.

MARGARET M. HECKLER, DEFENDANT.

AFFIDAVIT

STATE OF NEW YORK)
) ss:
COUNTY OF NEW YORK)

PETER A. M. AULD, M.D., being first duly sworn, deposes and says:

1. I am Director of the Perinatalogy Center at New York Hospital, 525 E. 68th Street, New York, New York 10021. The Perinatalogy Center treats several hundred infants each year with medical conditions that cannot be adequately treated at other hospitals which lack our equipment and medical expertise. I also am a Professor of Pediatrics and Obstetrics and Perinatal Medicine at Cornell University Medical College. I am a practicing Neonatalogist, and a member of several medical societies, including the American Medical Association, the American Academy of Pediatrics, and the American College of Obstetrics and Gynecology.

2. My patients include infants born with severe congenital conditions and handicaps such as Down's syndrome with accompanying complications or neural tube defects such as anencephaly and spina bifida, as well as low birth weight babies. Treatment of such infants requires difficult medical/ethical judgments. In most cases, treatment decisions are clear because treatment is expected to clearly benefit the infant. In some cases, however, certain medical treatments such as surgery, respirator treatment or IV's may offer little or no hope of improving the infant's condition, but may increase the pain and suffering of the infant.

3. In my practice, I treat an average of 800 infants each year with life-threatening conditions. Despite the fact that modern medical technology has improved the outlook for many such infants, the prognosis for many of these seriously ill infants remains extremely bleak regardless of the treatment provided.

4. Medical advances in recent years have made it possible to sustain the lives of some infants with severe medical problems for a short period of time. However, the availability of such new treatment creates a serious dilemma for the parents, who have the legal responsibility to make decisions regarding consent to the use of any particular course of medical treatment. Parents look to the hospitals, the physicians, the nurses and others to provide medical judgment for making decisions in these circumstances.

5. As a physician, I have a legal and ethical role in counseling parents about options for treatment, and I am in a unique position to identify those options to parents of newborns. The ultimate decision as to whether a particular treatment with dubious therapeutic value should be commenced must be made by concerned and loving parents, after they have been fully advised as to the expected outcome of any particular course of treatment. In all cases which I have been connected with, the parents, relying on the professional judgment of physicians and the counsel of clergy, are best able to make these difficult decisions.

6. In all my cases involving seriously ill newborns, treatment requires a trusting and open relationship between the parents of the newborn and the physician. Federal intervention in the complicated and delicate relationship between parents and physicians directly impairs this sensitive relationship. The parent-physician relationship is particularly important where parents must make decisions about the treatment and care of severely ill infants—particularly those infants with life threatening disorders for which particular courses of medical treatment do not have a high likelihood of success. Decisions regarding medical treatment of such infants involve complex clinical facts, difficult moral dilemmas and necessarily imprecise judgments. Federal involvement in these issues is both inappropriate and unhelpful.

7. Despite the inappropriateness of any Federal involvement in this area, the Department of Health and Human Services published comments and regulations on January 12, 1984 at 49 Fed. Reg. 1622 entitled "Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants" which injects federal involvement into the treatment of newborn infants with severe medical conditions. I have carefully reviewed those comments and regulations and have determined that they undermine the trusting parent-physician relationship needed to treat severely ill infants, and impose obligations on physicians which impair their ability to care for such infants.

8. The regulations impose two immediate duties on physicians. First, physicians are required to report to state agencies instances of suspected "medical neglect" in the care of newborn infants whenever "nourishment and medically beneficial treatment" are withheld from "handicapped infants solely on the basis of their present or anticipated mental or physical impairments." Second, physicians are required to assist in any investigations which may be conducted under these regulations, and must make confidential medical records available to investigators without the consent of the parents.

9. Unfortunately, crucial terms included in the regulations are so vague and undefined that I have no idea what my precise obligations are. "Medically beneficial treatment," for example, requires a difficult judgment which cannot be separated from the overall condition of the patient (including handicapping conditions). It is unclear what happens when my judgment differs from the judgment of the Federal government as to the proper course of treatment in such cases. This vagueness and uncertainty causes me immediate injury.

10. The existing requirement that I report to state agencies "suspected" cases of medical neglect is causing me immediate confusion and anxiety. The existence of that duty, regardless of whether I will actually need to report any cases, undercuts my ability to practice medicine. The reporting duty impinges on the confidentiality of my parent-physician relationship. Uncertainty and confusion over the meaning of important terms in the regulation causes me anx-

iety and emotional distress as to the precise nature of my duty to report. The standards of the federal regulations and of state law create a conflicting duty with regard to my duty to advise parents of the best treatments, and my duty to report "suspected" cases of medical neglect. This reporting requirement thus causes me immediate injury by imposing a vague duty which undercuts my ability to practice medicine.

11. The challenged regulations also adversely impact my practice today by threatening court involvement in "suspected" cases of neglect. The threat of court involvement affects my ability to counsel parents as to the best course of medical treatment in particular cases.

12. The regulations also cause me immediate injury because my patients and I are subject to intrusive federal investigations triggered by unverified telephone tips to a Federal "hotline" or reports to state agencies which trigger a Federal or state investigation. Such investigations can be initiated by tips from individuals who are completely unfamiliar with the facts of an individual case. As the comments to the regulations demonstrate, none of the investigations conducted by the Federal Government under Section 504 has resulted in any findings of wrongdoing. These baseless investigations, however, obtain the medical records of patients without the parents' consent, invade the confidential parent-physician relationship and violate the right of privacy of the family of the infant.

13. The ambiguity of the regulations and the potential for baseless investigations also causes immediate injury because they affect the course of treatment in individual cases. For example, I am forced to recommend over-treatment in some cases to avoid investigations as to whether failure to recommend such treatment constitutes discrimination. Such over-treatment is not in the best interests of the impaired infants—or in the best interests of infants who may be deprived of prompt treatment because limited medical resources are devoted to hopeless cases.

14. I am also injured by the present and threatened injuries to parents of severely impaired infants. Physicians have the duty to assert the rights of the parents of the medically impaired infant. That duty is especially important here be-

cause it is unrealistic to expect parents of impaired infants to have the resources or the time to challenge the unlawful intrusion of the Federal Government at the time of an investigation into the treatment of their infants. Physicians such as Neonatalogists and Pediatricians are uniquely qualified to represent the interests of parents of newborn infants with severe medical conditions.

15. Parents of infants are injured because the challenged regulations constitute a federal attempt to legislate the outcome of these difficult and complex decisions involving critically ill newborns. Such federal intervention undermines the parent-child relationship, disrupts the confidence parents have in their infants' physicians, and inappropriately seeks to resolve complex medico-ethical disputes through litigation.

16. Court litigation at the time decisions are made generally cannot improve the quality of the parents' decision. Rapid changes in the infant's condition create substantial uncertainties with respect to the likelihood of successful treatment and the consequences of unsuccessful treatment. Objective parties can legitimately disagree as to whether a particular course of treatment is in the best interest of the child.

17. In those instances where the parents refuse to consent to painful treatments of handicapped infants which would not, in my judgment, benefit the infant, I am required by the regulations to refer the matter to an appropriate state agency. My obligation to refer such cases to state agencies undermines my professional relationships with the parents of all seriously ill infants under my care. State agency investigators invade the privacy of the involved family and subject the family, hospital and staff to adverse publicity. The family may be forced to incur legal fees to justify its action to a court considering a petition to appoint a temporary guardian for the infant.

18. If an investigation is commenced, the portion of my time spent cooperating with the investigators is lost to patient care. Investigators frequently review charts which are then unavailable to medical personnel. As a result, the length of stay in the hospital of certain patients may be ex-

tended during such investigations.

19. New York Hospital is considering creation of an Infant Care Review Committee to help respond to these dilemmas. Such a committee would review decisions to withhold treatment, provide information to parents and physicians, consult with parents and physicians regarding treatment decisions, and in appropriate circumstances refer cases to state agencies. The committee also would provide a formal channel for hospital personnel and physicians to question orders in particular cases and review policies in a manner which preserves parent-physician confidences, protects the privacy of the involved families and avoids adverse publicity.

20. The new regulations directly undermine the purpose and usefulness of such Infant Care Review Committees. Rather than proceeding through the Committee, anyone can trigger a Federal investigation by simply calling the toll-free hotline. The resulting investigation undermines parent-physician confidences, invades the privacy of involved families and generates adverse publicity for both the Hospital and the involved families.

21. Throughout my medical career, I am unaware of a single case where the regulations could have improved the difficult decisions made by parents in consultation with their infant's physicians. However, I am aware of several difficult cases where I would have been forced to alter my recommendations and actions to the immediate detriment of the critically ill infant, the parents, and other critically ill infants requiring treatment. These regulations thus have an immediate and irreparable adverse impact on patient care.

FURTHER AFFIANT SAYETH NOT.

/s/ _____

Subscribed and sworn to before me this 6th day of March, 1984.

NOTARY PUBLIC
[SEAL]

APPENDIX K

UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF NEW YORK

Civil Action No.

AMERICAN MEDICAL ASSOCIATION, ET AL., PLAINTIFFS,

v.

MARGARET M. HECKLER, DEFENDANT.

AFFIDAVIT

STATE OF NEW YORK)
) ss:
COUNTY OF NASSAU)

RITA GILMAN HARPER, M.D., being first duly sworn, deposes and says:

1. I am Chief, Division of Perinatal Medicine, North Shore UniversityHospital, 300 Community Drive, Manhasset, New York. I am a practicing Neonatalogist and also serve as Consultant in Perinatal Medicine at the following hospitals: Wyckoff Heights Hospital, Brooklyn, New York; Southside Hospital, Bay Shore, New York; Brookhaven Memorial Hospital, Patchogue, New York; and St. John's Episcopal Hospitals, Smithtown and Far Rockaway, New York. I am Associate Professor of Pediatrics and Obstetrics and Gynecology at Cornell University Medical College. I am a member of the American Medical Association, the American Pediatric Society, and a Fellow of the American Academy of Pediatrics. I currently am Chairman, Committee on Fetus and Newborn, Chapter 2, District II of the American Academy of Pediatrics. I have published numerous articles relating to the care of infants born with severe medical conditions.

2. My patients include infants born with severe congenital conditions and handicaps such as Down's syndrome with accompanying complications or neural tube defects such as anencephaly and spina bifida, as well as low birth weight babies. Treatment of such infants requires an extensive medical background as well as difficult medical/ethical judgments. In most cases, treatment decisions are expected to benefit

the infant. In some cases, however, certain medical treatments such as surgery, respiratory treatment or IV's may offer little or no hope of completely correcting the infant's condition and are therefore directed toward supporting the infant's life functions. Indeed, at times, certain commonly administered therapies such as oral feedings will actually worsen an infant's condition and therefore, it is in the infant's best interest to forego oral feedings.

3. Medical advances in recent years have made it possible to sustain the lives of some infants with severe medical problems for a short period of time. It is through these attempts that in the long run, progress is made in developing new modalities for the treatment of infants and young children. For example, when I was in my first year of medical school, 95% of infants who weighed two pounds at birth died within the first twenty-eight days of life and 5% survived; now 95% survive and 5% die in the same time period. These data show that perinatal mortality has been significantly reduced in the last ten to fifteen years largely because Neonatologists have dedicated their lives to improving the medical care of critically ill infants. Advances in medicine are such that what is not feasible today will become feasible in the near future through advances in medical knowledge and therapy. There remain cases, however, where, no matter how hard the Neonatologist tries, the infant cannot be saved. For example, under our current knowledge of physiology and available treatment modalities, we are not able to save an infant with a birth weight of 350 grams.

4. The availability of new treatments creates a serious dilemma for the parents, who have the legal responsibility to make decisions regarding consent to the use of any particular course of medical treatment. Parents look to the hospitals, the physicians, the nurses and others to provide necessary knowledge and medical background for making these decisions. The ultimate decision as to whether a particular treatment should be commenced must be made by concerned and loving parents, after they have been fully advised as to the expected outcome of any particular course of treatment. In all cases which I have been connected with, the parents,

relying on the physician's experience and expertise and the advice of clergy, are able to make these difficult decisions.

5. As a physician, I have a legal and ethical role in counseling parents about options for treatment, and my twenty years as the Neonatalogist in charge of a neonatal intensive care unit give me the basis to identify those options to parents of newborns. These difficult treatment decisions are best resolved by parents and physicians.

6. Despite the fact that these decisions are best resolved by parents and physicians, the Federal Government recently has sought to control these decisions. The most recent mechanism for injecting Federal control is described in the comments and regulations published by the Department of Health and Human Services on January 12, 1984 at 49 Fed. Reg. 1622 entitled "Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants." I have reviewed those comments and regulations and determined that they will in no way increase the quality of care for infants with severe medical problems. Indeed, the regulations impose new requirements on Neonatologists and other physicians which will reduce their availability for the care of infants.

7. Those regulations impose two immediate duties on physicians. First, physicians are required to report to state agencies instances of suspected "medical neglect" in the care of newborn infants whenever "nourishment and medically beneficial treatment" are withheld from "handicapped infants solely on the basis of their present or anticipated mental or physical impairments." Second, physicians are required to assist in any investigations which may be conducted under these regulations, including making confidential medical records available to investigators.

8. Unfortunately, crucial terms included in the regulations are so vague and undefined that I have no idea what my precise obligations are under the regulations. For example, as part of the best standard of medical care, oral nourishment is routinely withheld from some infants with gastrointestinal malformations, infections, respiratory distress and other entities whether or not the infant has present or anticipated mental or physical impairments. Should these be reported?

What might be considered medical neglect by one physician would be considered adequate therapy by another. Moreover, I routinely administer therapies to infants which I consider will be beneficial to the infant. Any obligation to refer cases of "suspected medical neglect" where someone could claim that I was withholding beneficial treatment is incongruous with the way I practice medicine daily.

9. The requirements that I report to state agencies "suspected" cases of medical neglect undercuts my ability to practice medicine. In all cases involving seriously ill newborns, treatment requires an extensive dialogue and a trusting and open relationship between the parents of the newborn and the physician. The regulations directly impair this sensitive relationship by implying that the physician has not disclosed the facts adequately and that there is a physician somewhere with superior knowledge and ability. Decisions regarding medical treatment of such infants involve complex clinical expertise, difficult moral dilemmas and necessarily imprecise judgments. Federal involvement in these issues is both inappropriate and unhelpful.

10. These regulations also impede the advancement of medicine. Neonatologists will not be able to develop new treatments and methods of care for infants with severe medical complications while the Federal Government is looking over their shoulders. Fear of the consequences of unsuccessful attempts will thwart the efforts which are essential for progress in the treatment of infants.

11. Many hospitals, including North Shore University Hospital, have responded to the dilemmas posed by these cases by establishing Infant Care Review Committees. These committees review decisions to withhold treatment, provide information to parents and physicians, consult with parents and physicians regarding treatment decisions, and in appropriate circumstances refer cases to state agencies. These committees also provide a formal channel for hospital personnel and physicians to question orders in particular cases and review policies in a manner which preserves parent-physician confidences, protects the privacy of the involved families and avoids adverse publicity.

12. The new regulations directly undermine the ability of the Infant Care Review Committee to assist in these matters. Rather than proceeding through the Committee, anyone can trigger a Federal investigation by simply calling the toll-free hotlines. Such a course undermines the Committee, destroys the parent-physician relationship, invades the privacy of involved families and generates adverse publicity for the involved families.

13. Objective parties can legitimately disagree as to whether a particular course of treatment is in the best interest of the infant. The optimal treatment in any given case is a function of the available equipment, the physician's knowledge of the disease and treatment modalities, and of crucial importance, the physician's ability to practice the "art" of medicine. The challenged regulations adversely impact upon my practice today by threatening court involvement in "suspected" cases of neglect where someone else's detached hindsight substitutes for the judgments I make during the course of therapy. The regulations also immediately affect me by infringing upon my right to practice medicine according to my professional judgment and medical ethics.

14. As a physician, it is my duty to assert the legal rights of my patients and their families. Physicians must raise these rights because parents in an individual case will not have the time or resources to defend their rights. Moreover, the challenged regulations directly affect me as a physician by interfering with the confidential patient-physician relationship. The threat of governmental involvement reviewing my treatment decisions affects my ability to counsel parents as to the best course of medical therapy.

15. Investigations triggered by these regulations invade the privacy of the involved family and subject the family, hospital and staff to adverse publicity. The family may be forced to incur legal fees to justify its action to a court considering a petition to appoint a temporary guardian for the infant. If an investigation is commenced, the portion of my time spent cooperating with the investigators is lost to patient care. This may be the very critical time needed by the infant. As a result, quality of care may be severely jeopardized.

16. The challenged regulations constitute a Federal attempt to legislate the outcome of the difficult and complex decisions involving critically ill newborns. Such Federal intervention undermines the parent-child relationship, disrupts the confidence of parents in their physicians, and inappropriately seeks to resolve complex medico-ethical disputes through litigation.

17. Throughout my medical career, I am unaware of a single case where the regulations could have improved the difficult decision made by parents in consultation with their infant's physicians. However, I am aware that a "Big Brother" overseer in the nursery will inhibit application of new therapies for the care of infants, will interfere with critical care support systems offered to infants, will destroy the parent-physician relationship, and will foster the development of a new bureaucracy. The money spent in administering these regulations would offer much greater benefit if devoted to perinatal research. These regulations have an immediate and irreparable adverse impact on the care of the newborn.

FURTHER AFFIANT SAYETH NOT.

/s/ _____

Subscribed and sworn to before me this 7 day of March, 1984.

/s/
Notary Public
[SEAL]

APPENDIX N

AFFIDAVIT

Paul M. Rosenberg, having been duly cautioned and sworn, hereby states that:

1) He resides at 12 Pickford Drive, Rochester, New York, and is employed by Strong Memorial Hospital of the University of Rochester, Rochester, New York, as Associate Director, Fiscal and Administrative Services. Responsibilities of this position include the legal affairs of the Hospital, and entail contact with the representatives of regulatory and investigative agencies. Additionally, affiant takes administrative call for the Hospital on a scheduled basis, responding to unusual situations.

2) The Hospital is in compliance with the requirements for posting notice of the "Infant Doe Hotline" number and other information as required by 45 CFR Part 84, § 84.61, Amended.

3) During the week of March 28, 1983, he was assigned to take administrative call for the Hospital, and that on March 29, 1983, at approximately noon, he received a call from an individual identifying himself as Alan Brotman, Investigator, Office for Civil Rights, Department for Health and Human Services, New York Regional Office.

4) Mr. Brotman advised him that a Washington hotline call had been received by his agency, reporting that conjoined (siamese) twins were admitted to Strong Memorial Hospital and that said twins might be denied nutrition or treatment, and that said report triggered a duty on the part of Mr. Brotman to conduct an investigation, which would begin that afternoon. When asked the nature of said hotline report, Mr. Brotman indicated that a caller from Binghamton, New York had read of the twins' admission in a local newspaper, that the newspaper account indicated that said twins might not survive, and that the caller provided no information beyond that contained in the newspaper account. Mr. Brotman could not provide details, and contact with the Washington Office produced a promise to provide the time of call, name of person who received the call, and a transcript or summary of the facts reported or allegations made by the caller. Mr.

Brotman proceeded to ask preliminary medical questions about said patients. After verifying Mr. Brotman's identity with his supervisor, Mr. David Coronado, affiant answered those questions to the best of his ability. Mr. Brotman then left his office to make travel arrangements to Rochester.

5) Mr. Coronado, in a separate telephone conversation, assured affiant that Mr. Brotman would bring a written request for information in this matter, along with a written statement of his authority. During this conversation, Mr. Coronado also advised that a second investigator, Ms. Zulma Soto, would accompany Mr. Brotman.

6) Affiant then set about obtaining certain information which had been requested for review by Mr. Brotman including a copy of medical records, with patient identification information deleted, and certain Hospital policy information. He also arranged to make the patient's attending physician available for interview by the investigators.

7) Prior to the arrival of Mr. Brotman and Ms. Soto, affiant was again contacted by Mr. Coronado, who advised that an investigator from his agency's Washington, D.C. headquarters, Carole L. Brown, would be joining the New York investigators.

8) Ms. Brown arrived at Strong Memorial Hospital at approximately 4:00 PM and that investigators Brotman and Soto arrived at approximately 4:30 PM, and that none of them delivered any written request for information, verification that a phone call had been actually made to the Washington hotline, or written statement of investigative authority. The investigators presented their investigative identification materials only.

9) After review of investigative credentials, affiant provided the aforementioned medical records copy for review by the investigators and answered their questions. The investigators then disagreed among themselves as to which of their offices was entitled to the copy of the medical records. The patients' attending physician was then made available for a lengthy interview about the patients' condition, care, decision-making, involvement of the family in decision-making, and other items of confidential information.

10) While said interview took place, the investigators were advised by telephone that a neonatologist would be sent to Rochester that evening to assist with their investigation. After some confusion, the neonatologist was identified as Dr. Frederick Wirth of Norfolk, Virginia. Requests for interviews with other staff members were denied by affiant, and it was agreed that further inquiry would await arrival of Dr. Wirth.

11) Upon learning that a physician was being dispatched, and upon the presumption that he would request to examine the patients, and upon learning that a report of the investigation being conducted by the federal agency was being carried on local news media, affiant advised the attending physician to contact the patients' parents and solicit their views on further cooperation with the investigation, and particularly, as to whether they would authorize an examination of the patients by Dr. Wirth.

12) Dr. Wirth arrived in the Rochester area, conferred with the investigative team, and telephoned the affiant at approximately 10:00 PM to advise that he wished to examine the infants and review the medical records.

13) Affiant advised Dr. Wirth that the Hospital would not authorize such examination without consent of the patients' parents, and that Dr. Wirth stated that he was surprised that no authorization had been obtained, as he had believed that the investigative team would obtain written authorization for examination by the physician investigator. Dr. Wirth stated that he had discussed the case with the investigators based on their notes and recollections from the afternoon's record review and interviews, and that based on that discussion he was fully supportive of the medical decision-making, level of parental involvement in said decision-making, and overall patient management in the case.

14) The attending physician conferred further with the patients' parents at 8:00 AM on March 30, and was advised that the parents opposed examination of the patient by a physician member of the investigative team. This refusal was communicated to Dr. Wirth by affiant, and also to Carol Brown. Dr. Wirth advised that he would not be involved further in the case. Ms. Brown advised that the team had been

instructed to return to its respective offices in the event there was a refusal of further cooperation with the investigation.

15) No written communication regarding the request for information, the nature and scope of the investigation, or verification that a hotline report was actually made has been received by Strong Memorial Hospital. Despite direct telephone inquiry by the affiant to Mr. Brotman and Ms. Brown, the agency has been unable to advise affiant and the Hospital as to which office will be responsible for completing the investigation, preparing a report, and closing the investigative file.

16) Despite an informal verbal assurance to the affiant that all was found to be in order by the investigating team, and that no violation of any federal regulation would be found, the investigative agency can give no prediction of when it will be prepared to make public statements or a statement to the patients' family to that effect, countering the traumatic effect of this invasion of the family's privacy and of numerous newspaper accounts of the investigation which appeared in the Rochester region. The confusing and disorganized approach taken by the Agency in investigating and following up this complaint has compromised the Hospital's ability to assist the family of infants born with profound congenital malformations in formulating an appropriate care plan, due to the fact that the family now feels that any decisions it makes will be subject to similar scrutiny. The harm caused by the Agency's loose and ill-defined investigative and administrative procedures extends beyond this one tragically affected family. Parents of other critically ill children have questioned whether the Hospital is intentionally harming children, and on April 1, one family withdrew a seriously ill patient from the Hospital before completion of treatment due to fears that the Hospital was intentionally harming children, caused by their reading of local newspaper accounts of the investigation.

On April 1, 1983, Paul M. Rosenberg appeared personally before me, a Notary Public licensed in the State of New York, and swore that the above was his own truthful statement, and signed in my presence.

/s/ _____ /s/ _____

Notary Public PAUL M. ROSENBERG

APPENDIX O

IN THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF COLUMBIA

Civil Action No. 83-0774

AMERICAN ACADEMY OF PEDIATRICS; NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, INC.; AND CHILDRENS HOSPITAL NATIONAL MEDICAL CENTER, PLAINTIFFS,

v.

MARGARET M. HECKLER, SECRETARY OF THE UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, DEFENDANT.

AFFIDAVIT OF NORMAN B. URMY

I, Norman B. Urmy, being first duly sworn makes oath as follows:

1. I am Director of the Vanderbilt University Hospital and have held this position since August of 1982. I am providing this affidavit at the request of the National Association of Childrens' Hospitals for use in its lawsuit against the Department of Health & Human Services ("HHS"). The purpose of this affidavit is to describe a site investigation by the Office of Civil Rights ("OCR") of HHS on March 23 and 24, 1983 in response to an anonymous call to the hotline established by HHS. This affidavit is based on my personal knowledge and on information given me by Dr. David Karzon, Chief of Pediatrics, Ms. Sharon Cox, Associate Director of Nursing for Children's Hospital and other members of the Hospital staff.

2. In the early afternoon of Wednesday, March 23, Vanderbilt University Hospital was called by Ms. Mildred Wise of OCR's Atlanta Regional Office. Ms. Wise said that an individual had used the hotline to report that Vanderbilt University Hospital was not providing proper medical treatment or proper nourishment to ten named children at the

Hospital. Ms. Wise asked for information concerning the current medical status, diagnosis and prognosis of each of these ten children and requested that the information be provided within one hour. We informed her that we would give OCR the information but that it could not be done within one hour. Ms. Wise stated that federal investigators planned to catch the next available flight to Nashville and would like to meet with Hospital officials and physicians at 9:30 p.m., the night of March 23.

3. We were informed that the site inspection team would consist of two investigators from OCR Atlanta, one investigator from OCR Washington and a physician/consultant, Dr. William Keenan, a neonatologist with the Cardinal Glennon Children's Hospital in St. Louis, Missouri.

4. On the afternoon of March 23, Ms. Cox reviewed the files of the ten patients and, based on her report, we concluded that there was no medical basis for the call, since all ten patients were receiving complete, aggressive and excellent medical care. In particular, all ten patients were receiving nourishment.

5. We contacted the attending physicians for each of the ten children, explained the situation to them, and invited them to the initial meeting with the OCR investigators. The meeting, which I attended for most of the time, began at 9:30 p.m. and continued until approximately 11:45 p.m. The attending physicians and the Chief Pediatric Resident (to the extent that the attending physician could not attend) discussed the medical history, course of treatment, nourishment and prognosis of each of the ten children utilizing the medical record.

6. After the meeting, Dr. Karzon and the Chief Pediatric Resident, and Dr. Keenan, the OCR physician/consultant, made "rounds" to visit each of the patients.

7. On the following day, March 24, the OCR team arrived at the Hospital at approximately 8:00 a.m. and stayed until 4:00 p.m. Hospital records of the ten children were made available to them for their review in detail. The investigators had indicated they wanted to personally review the medical records in order to verify the information provided to them verbally the night before by the attending physi-

cians and Chief Pediatric Resident. The investigators also interviewed nursing staff (supervisory and other primary care nurses), Hospital administration, and the Chief of Pediatrics.

8. On March 24, we asked the OCR team for a preliminary report as to their findings. (A similar request was also made at the meeting the night before.) The OCR team refused and said that we would have to await their final report, which would be issued within the next thirty to ninety days. The OCR team, however, expressed no concern about any of the ten patients and certainly took no action to "protect" any of them.

9. Dr. Keenan, the OCR physician/consultant, made the following statement to us: "The care of the ten children at Vanderbilt University Hospital is exemplary, supportive both biologically and psychologically in all respects." Dr. Keenan emphasized that these were his personal medical opinions and that they did not necessarily reflect what would appear in the final official report to be issued by OCR.

10. Although the OCR team conducted themselves in a professional manner and Vanderbilt attempted to cooperate with them, the investigation was time consuming, disruptive and indirectly expensive. Dr. Karzon worked eight hours with the OCR team; Ms. Cox worked eighteen hours assisting them. The Chief Pediatric Resident spent ten hours assisting the OCR team. Six nurses on our staff were interviewed by the OCR team for a total of three hours. These doctors and nurses would have otherwise spent their time caring for patients.

11. Most importantly, however, the OCR investigation had adverse effects on medical care given the ten patients involved.

(1) One patient remained in the Pediatric Intensive Care Unit longer than necessary because his chart was unavailable for the housestaff to review and write discharge orders.

(2) On March 24, the housestaff were unable to review laboratory reports and update orders following rounds since the charts were in the possession of the OCR team. Copies of laboratory reports had to be ordered and numerous calls were required to the laboratory to obtain information.

(3) There were delays in the transporting of patients from the Pediatric Intensive Care Unit to the Operating Room since charts had to be retrieved from the investigators.

(4) Six nurses were pulled from patient assignments for interviews with the OCR team. Several of these interviews occurred during changes of shifts, which delayed reports on patients to the nurses on the next shift.

For these reasons, there was disruption of Hospital activities and patient care, and patient safety was placed in potential jeopardy by the OCR investigation.

FURTHER AFFIANT SAITH NOT.

I declare under penalty of perjury under the laws of the United States that the foregoing statements are true and correct.

DATED this 5th day of April, 1983.

/S/ Norman B. Urmy
NORMAN B. URMY

STATE OF TENNESSEE)

COUNTY OF DAVIDSON)

Sworn to and subscribed before me this 5th day of April, 1983.

/S/ John C. Cellison
JOHN C. CELLISON
Notary Public

My Commission Expires: July 27, 1986.

Excerpts from:

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*

Chapter 6, "Seriously Ill Newborns," pages 223-229.

Policy Evaluation and Recommendations

The few systematic studies of decisionmaking about seriously ill newborns support the contentions of care professionals before the Commission and elsewhere that such decisionmaking usually adheres to the precepts outlined in this chapter.[90] As shown previously, however, problems of two kinds do occur: (1) parents receive outdated or incomplete information from their physicians and this limits their capacity to act as surrogate decisionmakers,[91] and (2) in what appears to be a limited number of cases, inappropriate decisions are made without triggering a careful reevaluation.[92]

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[90] *See* notes 46-49 *supra*.

[91] Hein, *supra* note 74.

> When they [parents] begin to hear both points of view—sometimes it's only that there are excellent adoptive homes for such kids—that's often never raised—that changes the decision. Sometimes they just need to learn more about Down's. Parents have such horrible fantasies about it; it's mongolism and it's something monstrous, they think. This wider process is often nothing more exotic than bringing facts into the discussion.

Testimony of Dr. Norman Fost, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 161.

[92] Robertson, *supra* note 76. Perhaps the best-known case, and the only one in which there is an appellate court decision, is the one that has come to be known as the Infant Doe case, in which parents elected to forego treatment of their newborn child who had Down syndrome, tracheoesophageal atresia, and possibly additional anomalies. The course of nontreatment was one "medically recommended" way in which to proceed, according to the opinion of the trial court in an action brought by child welfare authorities on the complaint of some party other than either the physicians or the parents of the child. The trial court eventually sustained the parents' decision not to treat. *In re* Infant Doe, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. April 12, 1982), *writ of mandamus dismissed sub nom.* State *ex rel.* Infant Doe v. Baker, No. 482 S

Improving Initial Decisions. The Commission believes that professional associations and health care institutions should help ensure that the best information is available and is used when decisions about life-sustaining treatment are made.[93] This is especially important in the cases of neonates because of both rapidly expanding medical capabilities and other efforts to maximize the potential of the disabled. Physicians should seek, and institutions might require, specialist consultations in such cases.

Where problems arise in communication between parents and nurses or physicians, institutions should provide responsive means to improve the communication and resolve the impasse. A high priority for care givers in this area should be the development of personal and team skills in communication and the enhancement of surrogates' capacities for effective decisionmaking.

Ensuring Appropriate Review. Although personal morality and compassion, high standards of professional ethics, and current laws and regulations ensure that the vast majority of decisions about seriously ill infants are made correctly and that incorrect decisions are redressed, occasionally actions are taken without the consent of an infant's surrogate or tragically erroneous decisions are made by both physicians and surrogates. Judicial proceedings provide a possible means to handle these situations, although the Commission does not find them to be the best—nor even a very available and convenient—method.

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140 (Indiana Supreme Ct., May 27, 1982) (case mooted by child's death). Assessing this case is made difficult by the privacy concerns involved in judicial proceedings. *See* Steven R. Valentine, *Briefs Ordered Sealed in "Infant Doe" Appeal Case*, RIGHT TO LIFE NEWS, Nov. 24, 1982, at 8.

[93] You were asking if it is possible to do it [counsel parents of seriously ill newborns] without a team.... I can't imagine doing it without a team, frankly, because there are so many different parts of each parent that need attending to in a decision that is the most excruciating one they will ever make, and no one professional discipline can do all of that.

Testimony of Carol Kennon, Social Worker, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 31. *See also* Hein, *supra* note 74.

Actions taken without a surrogate's consent are not readily susceptible to redress through the courts, since the parents are not likely to be in a position to evaluate—or even to detect—what is happening in their child's care if they are excluded from decisionmaking; furthermore, civil proceedings would be cumbersome, costly, and slow.[94] In many institutions, people concerned about erroneous decisions by both physicians and surrogates intervene only by complaining to public officials that child abuse or criminal homicide has occurred or may be about to occur. This very serious accusation usually requires that the complainant believes the evidence is sufficient to warrant legal action.

Furthermore, the adversarial atmosphere generated by this approach is unlikely to lead to infants receiving the most suitable care. The same problem arises with the regulations issued by the Department of Health and Human Services in

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[94] I think we have . . . a real contrast in time-frame analysis between the medical and legal profession. . . . When we talk about quick court decisions we are talking about 12 days. When I talk about quick, it means running down the stairs rather than taking an elevator. . . . You have to understand when physicians want an answer they want it in 10 minutes. When lawyers produce an answer, they congratulate themselves for producing it in 10 days.

Testimony of Dr. Marianne Prout, transcript of 10th meeting of the President's Commission (June 4, 1981) at 35-36; Arnold Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 L. & MED. 233 (1978).

In addition to being ill-equipped to respond quickly enough to life-threatening situations, courts have been criticized for being unable to respond to the dynamic nature of decisionmaking necessary for medical treatment choices. *Compare* the statement of I. David Todres in Cynthia B. Wong and Judith P. Swazey, eds., DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT, G.K. Hall Med. Pub., Boston (1981) at 122-23 *with* Maine Medical Center v. Houle No. 74-145 (Super. Ct. Cumberland County, Me., Feb. 14, 1974) *reprinted in* Robert F. Weir, ed., ETHICAL ISSUES IN DEATH AND DYING, Columbia Univ. Press, New York (1977) at 185. *In re* Teague, No. 104-212-81886 (Cir. Ct. Baltimore, Md., filed Dec. 4, 1974) (child born with spina bifida died before action could be taken on the case.). *See* p. 159 *supra*.

the wake of the *Infant Doe* case[95] to prevent handicapped infants from being "discriminatorily denied food or other medical care."[96] Instead of adding further uncertainty to an already complex situation,[97] the Federal government would do

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[95] Office of the Secretary, Department of Health and Human Services, *Nondiscrimination on the Basis of Handicap*, 48 Federal Register 9630 (1983) (interim final rule modifying 45 C.F.R. § 84.61). *See also* Office for Civil Rights, Department of Health and Human Services, *Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice to Health Care Providers*, 47 Federal Register 26,017 (1982) (notice issued May 18, 1982, applying 45 C.F.R. Part 84 to health services for handicapped children), *reprinted in* Appendix H, pp. 467-68 *infra*.

Under the March 1983 notice, a warning must be posted in relevant places in hospitals that it is unlawful to exclude any "otherwise qualified handicapped individual" from the benefits of any Federally assisted program. A toll-free 24-hour "hotline" number is provided for anyone who knows of any handicapped infant who is being denied food or "customary medical care." Under the earlier notice, the Department reminded the nearly 7000 hospitals that receive Federal aid that existing HHS regulations apply § 504 of the Rehabilitation Act of 1973 to health services and treat Down Syndrome as a handicap within the meaning of § 504. Prior to 1982, § 504 had only been used once in the context of newborns with congenital anomalies. *See* Protection and Advocacy Agency of Hawaii v. Kapiolani Children's Hospital, Health and Human Services Doc. No. 09-79-3158 (1980), *cited in* Nancy Lee Jones, *Application of Section 504 of the Rehabilitation Act of 1973 to Handicapped Infants*, Congressional Research Service, Library of Congress, Washington (July 9, 1982).

[96] *Discrimination Against the Handicapped*, *supra* note 95, at 9630.

[97] Questions remain, for example, concerning such difficult matters as decisions regarding very low birth weight babies on the edge of viability, decisions for those with multiple serious congenital anomalies, and decisions for infants who are dying. Witnesses testifying before the Commission expressed concern that virtually every operative phrase of the DHHS directive needs amplification and would be subject to varieties of interpretation.

> There are two problems with Section 504: (1) it is not clear if or why a handicap can *never* be a justification for withholding treatment; and (2) the phrase "medically contraindicated" is ambiguous . . . the wording of this exemption is so vague that it is unintelligible. What is meant by a medical contraindication to treatment?. . . . The language of Section 504 does not tell us *whether* it is permissible to withhold dialysis from a hydranencephalic child, or *why* it is impermissible to withhold intestinal surgery from a child with Down Syndrome.

Norman Fost, *Putting Hospitals on Notice*, 21 HASTINGS CTR. REP. 5 (Aug. 1982). *See also, Life Support Notice Attacked*, AM. MED. NEWS,

better to encourage hospitals to improve their procedures for overseeing life-and-death decisons, especially regarding seriously ill newborns. Using financial sanctions against institutions to punish an "incorrect" decision in particular cases is likely to be ineffective and to lead to excessively detailed regulations that would involve government reimbursement officials in bedside decisionmaking. Furthermore, imposing such sanctions could unjustly penalize the hospital's other patients and professionals.

The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants; accrediting bodies could appropriately require this. Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. Other cases, such as when the physician and parents disagree, might well also be reviewed. The policy should allow for different types of review and be flexible enough to deal appropriately with the range of cases that could arise. Some cases may require only a medical consultation to confirm a diagnosis of an inevitably fatal condition, for example. In other cases, when the benefits of therapy are less clear, an "ethics committee" or similar body might be designated to review the decisionmaking process.[98] This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases. Cases included in this category should certainly encompass those in which a decision to forego life-sustaining therapy has been proposed because of a physical or mental handicap, as well as cases where a dispute has arisen among care givers and surrogates over the proper course of treatment.

Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify

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July 16, 1982 at 17 (response by American Academy of Pediatrics to the Section 504 directive).

Furthermore, the term "handicapped" is in no way limited in application to neonates. The impact of a regulation of this sort on the care of other patients could be substantially in conflict with this Report.

[98] *See* pp.160-70 *supra*.

that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate. Such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested "representative of the public" and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.

Insofar as possible, infants' lives should be sustained long enough to gather the best information and to permit expeditious review. When the parents and physician feel justified in acting without either or both of these conditions, as might happen with a rapidly deteriorating medical status, retrospective review should be undertaken.[99] Unlike turning to the courts for scrutiny of every case involving treatment of a seriously ill newborn, review of this limited category of cases would not seem likely to generate inappropriate social or financial costs.

In light of the lack of comprehensive information about decisionmaking practices and the fact that the Commission's recommendation is largely untried, the Commission encourages institutions, social scientists, and funding agencies to evaluate the effectiveness of such regularized review in order to improve its efficiency and efficacy and to refine the definition of the circumstances in which it is needed.

Long-Term Implications. The value society places on promoting the health and welfare of children has ramifica-

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[99] Ensuring a retrospective review removes any incentive for hasty actions to avoid prospective review, a course that could be a disadvantage to at least some newborns. Retrospective review cannot change what happened to a particular child, but it can help ensure a high standard of decisionmaking practices in the institution and can censure seriously erroneous decisionmaking, both internally and by referral to the courts.

tions beyond neonatal intensive care units. When the decision is made to give seriously ill newborns life-sustaining treatment, an obligation is created to provide the continuing care that makes a reasonable range of life choices possible. A major conference on critically ill newborns concluded:

> The advocates of intensive care must become the advocates for development of humane continuing care and for sufficient funding of programs to support families whose children require special attention at home or in institutions. Neonatology cannot be developed in isolation from the continuing specialized care which, unfortunately, will be needed by some of the survivors of life-threatening neonatal disorders.[100]

Adoption and foster care should be available for parents unable to raise their seriously handicapped child.[101] To aid parents, support that is responsive to the emotional and financial demands of handicapped persons and their families should be available. As a physician who has been pioneer in the treatment of infants and children recently commented, such support is an essential concomitant to a commitment to sustaining life.

> I'm very much involved in making sure that habilitation and rehabilitation of spina bifida individuals is advancing, because that's really the hope. If . . . I have preserved a thousand children who are going to sit in wheelchairs in nursing homes with normal intelligence

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[100] Albert R. Jonsen *et al.*, *Critical Issues in Newborn Intensive Care: A Conference Report and a Policy Proposal*, 55 PEDIATRICS 756, 764 (1975).

[101] As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than *either assume* full responsibility for the treatment, care, and nurture of such children *or honor* the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life.

Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervision for the Child at Risk*, in Gaylin and Macklin, *supra* note 66, at 153.

> .... if that's what I've done, I've created a nightmare.[102]

Private organizations have made enormous contributions on behalf of the disabled; yet public funds may ultimately be needed so that these children, once rescued, are not then left to drown in a sea of indifference and unresponsiveness. Public support for effective voluntary organizations and governmental programs is the inescapable extension of society's deep interest in sustaining life in neonatal intensive care units. Furthermore, to the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised.

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[102] Dr. David McClone, Interview on *Sunday Morning* (transcript), CBS Network, Aug. 29, 1982, at 25.

Supreme Court of the United States

No. 84-1529

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

ORDER ALLOWING CERTIORARI. *Filed June 17, 1985.*

The petition herein for a writ of certiorari to the *United States Court of Appeals for the Second Circuit* is granted.

Supreme Court, U.S.
FILED
AUG 31 1985
JOSEPH F. SPANIOL, JR.
CLERK

No. 84-1529

In the Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF FOR THE PETITIONER

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QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, prohibits a hospital program receiving federal financial assistance from withholding nourishment or medically indicated treatment from a handicapped infant, or otherwise discriminating against the infant, solely because of his handicap.

PARTIES TO THE PROCEEDING

The petitioner is Margaret M. Heckler, the Secretary of Health and Human Services.

The respondents are the plaintiffs in two suits filed in the district court that were consolidated in that court and in the court of appeals. The plaintiffs in *American Hospital Association, et al.* v. *Heckler* are the American Hospital Association, the Hospital Association of New York State, and Strong Memorial Hospital of the University of Rochester. The plaintiffs in *American Medical Association, et al.* v. *Heckler* are the American Medical Association, the American Hospital Association, the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Academy of Family Physicians, and Drs. Hubert A. Ritter, Peter A. M. Auld, Rita Gilman Harper, and Roy Howard Petrie.

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ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF FOR THE PETITIONER

OPINIONS BELOW

The order of the court of appeals summarily affirming the judgment of the district court (Pet. App. 1a-3a) is unreported. The opinion of the court of appeals in *United States* v. *University Hospital* (Pet. App. 4a-47a), upon which both the district court and court of appeals relied in this case, is reported at 729 F.2d 144. The memorandum and order of the district court (Pet. App. 48a-49a) are reported at 585 F. Supp. 541.

JURISDICTION

The judgment of the court of appeals was entered on December 27, 1984. The petition for a writ of certiorari was filed on March 27, 1985 and was granted on June 17, 1985. The jurisdiction of this Court is invoked under 28 U.S.C. 1254(1).

STATUTORY AND REGULATORY PROVISIONS INVOLVED

1. Sections 7(7) (B), 504, and 505(a)(2) of the Rehabilitation Act of 1973, 29 U.S.C. 706(7)(B), 794, and 794a(a)(2), are reproduced in an Appendix to this brief, *infra*, 1a-2a.

2. 45 C.F.R. 84.55 and Pt. 84, App. C, as added by 49 Fed. Reg. 1650-1654 (Jan. 12, 1984), are reproduced at Pet. App. 53a-72a and J. A. 111-126, and the preamble to the regulations (49 Fed. Reg. 1622-1649 (1984)) is reproduced at J. A. 11-111.

STATEMENT

A. The Statutory and Regulatory Framework

1. In April 1982, a newborn child with Down's Syndrome was permitted to starve to death in Bloomington, Indiana, after being denied life-saving surgery to repair a blocked esophagus.[1] Following disclosure of the incident, which generated widespread public discussion and concern, the President directed the Secretary of Health and Human Services (HHS) to remind health care providers receiving federal financial assistance that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, prohibits discrimination on the basis of handicap in programs or activities that receive federal financial assistance. See 49 Fed. Reg. 1622-1623 (1984) (J.A. 14). On May 18, 1982, the Secretary sent such a notice to all covered health care providers, pointing out that then-existing HHS regulations (45 C.F.R. 84.52, 84.3 (j)) made clear that Section 504 applies to the provision of health services and that conditions such as Down's Syndrome are handicaps within the meaning of Section 504. 47 Fed. Reg. 26027 (J.A. 127-128).

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[1] In the Bloomington incident, "[the infant's] parents refused to consent to surgery[,] and the hospital turned to the state courts for guidance. Despite appointment of a guardian *ad litem* and several attempts at appeal, no judicial intervention occurred and the infant died six days later." *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 397 (D.D.C. 1983).

Subsequently, on March 7, 1983, the Department of Health and Human Services promulgated interim rules establishing certain procedures relating to the application of Section 504 to refusals to treat handicapped infants. 48 Fed. Reg. 9630. On April 14, 1983, those regulations were invalidated by the United States District Court for the District of Columbia. *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395. The district court in that case expressed the view that the broad language of Section 504 might well authorize some regulation of the furnishing of medical care to handicapped newborns. 561 F. Supp. at 402. However, the court concluded that HHS's decision to waive the public comment period when it promulgated the regulations violated the Administrative Procedure Act, 5 U.S.C. 553, and that the regulations were arbitrary and capricious because the administrative record failed to establish that several important factors had been adequately considered. 561 F. Supp. at 403-404.

2. HHS then published new proposed regulations on July 5, 1983. 48 Fed. Reg. 30846. After receiving broad public comment, HHS promulgated the regulations at issue here on January 12, 1984. 49 Fed. Reg. 1622 (J.A. 11). The 1984 regulations do not in themselves establish the applicability of Section 504 to the provision of health care to handicapped infants, because that applicability was "already established by the statute and the existing HHS regulations" (49 Fed. Reg. 1628 (J.A. 34)), which were promulgated in 1977 (42 Fed. Reg. 22677). HHS explained that those existing regulations expressly state that discrimination in the provision of health services to handicapped persons is prohibited by Section 504 (49 Fed. Reg. 1636 (J.A. 60), citing 45 C.F.R. 84.52), and that they define discrimination broadly to include the denial to a handicapped person of aid, benefits, or services equivalent to those afforded to others (48 Fed. Reg. 30847, citing 45 C.F.R. 84.4(b)(1)(i) and (ii)). Moreover, the Department stated that in 1980, it had enforced Section 504 against a hospital based on the hospital's withholding of surgery to correct an intestinal obstruction in a child with Down's syndrome. 48 Fed. Reg. 30847-30848. At the same time, HHS stressed

that Section 504 does not provide for "second guessing of reasonable medical judgments regarding medically beneficial care" (49 Fed. Reg. 1630 (J.A. 41)), but instead only embodies the principle that life and death medical treatment decisions must actually be based on such bona fide medical judgments, "not on stereotypes and prejudices against handicapped persons" (49 Fed. Reg. 1622 (J.A. 14)).

Against this background, the regulations at issue here contain two essential features: (a) guidelines setting forth HHS's interpretation of Section 504 in the particular context of a health care provider's failure to treat a handicapped infant, and (b) several procedural measures to implement that interpretation and bring about compliance:

a. *Interpretative Guidelines.* The regulations explain the application of Section 504 in this setting through interpretative guidelines that state four basic principles: (1) health care providers receiving federal financial assistance "may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment"; (2) "[f]utile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant" for purposes of Section 504: (3) "[i]n determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected"; and (4) if a parent withholds consent to treatment that is medically indicated, the hospital may not, solely on the basis of the infant's handicap, decline to report a suspected instance of medical neglect to the appropriate child protective services agency or to seek judicial intervention on behalf of the child. 45 C.F.R. Pt. 84, App. C. para. (a)(1)-(4) (J.A. 121-122). The purpose of these guidelines is only to provide an analytical framework within which to address the issues presented. Accordingly, HHS stressed that they would be "flexibly" applied "on a case-by-case basis with a full appreciation of the facts presented" (49 Fed. Reg. 1632 (J.A. 46); see also *id.* at 1629 (J.A. 35)).

With regard to the last of the four principles, the Department explained that Section 504 applies to the federally assisted health care provider, not to parents, and that "section 504 does not mandate that the hospital unilaterally overrule the parental decision and provide treatment notwithstanding the lack of consent" (49 Fed. Reg. 1631 (J.A. 44)). However, HHS reported that "[h]ealth care professionals are generally required by state law to report cases of abuse, neglect, or other threats to a child's health" and that "[m]ost hospitals have established procedures to petition courts to order medical care when parents do not provide consent for treatment that is medically needed and appropriate"—"where, for example, parents have objected on religious grounds to a medically necessary blood transfusion for their child" (*ibid.* (J.A. 43-44)). Because "[t]he requirement that health care providers report instances of improper denial of medical care is no less a part of their program than is the provision of care itself," HHS concluded that Section 504 prohibits a hospital from discriminating on the basis of handicap in carrying out that responsibility (*ibid.*).[2]

b. *Procedural Provisions.* The remainder of the regulations set forth procedural measures for the implementation of these protections under Sections 504. These measures are tailored in a number of respects to foster a cooperative effort

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[2] The guidelines also give illustrations of treatment decisions that would and would not violate Section 504. They state that the withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome, when the withholding is based upon the anticipated future mental retardation of the child and when there are no medical contraindications, would constitute discrimination in violation of Section 504. So, too, Section 504 would prohibit the withholding of treatment for medically correctable physical anomalies in children born with spina bifida if that withholding is based on the anticipated impairments of the child after the treatment, rather than on a bona fide medical judgment regarding the treatment itself. But the guidelines also state that the withholding of treatment for such conditions as anencephaly, spina bifida, and severe prematurity and low birth weight would not violate Section 504 if based on a reasonable medical judgment that the treatment would be futile or too unlikely of success given complications in the particular case, would create risks of potential harm to the infant, or would merely prolong the act of dying. 45 C.F.R. Pt. 84, App. C para. (a)(5)(i)-(iv) (J.A. 122-123).

on the part of the federal government, state governments, and the medical community.

i. The most detailed regulations outline voluntary steps hospitals could implement to carry out the principles of Section 504. Adoption of these steps could make the use of federal enforcement mechanisms unnecessary. In accordance with the recommendation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, as well as the comments of the American Academy of Pediatrics and the American Hospital Association (see 49 Fed. Reg. 1622, 1623-1625 (1984) (J.A. 13, 16-22)), the Secretary developed a model for hospitals that wish to establish an Infant Care Review Committee (ICRC) to assist in evaluating issues relating to the treatment of handicapped infants. 45 C.F.R. 84.55(a) and (f) (J.A. 112, 116-121).[3]

Under the proposed model, the ICRC would develop and recommend to the hospital various institutional policies concerning the withholding or withdrawal of treatment from infants with life-threatening conditions, including guidelines for management of certain categories of cases (*e.g.*, Down's Syndrome and spina bifida) and procedures to be followed in certain recurring circumstances (*e.g.*, brain death and parental refusal to consent to lifesaving treatment). 45 C.F.R. 84.55(f)(3)(i). The ICRC also would review specific cases in which a preliminary decision had been made to withhold or withdraw life-sustaining treatment from patients, such as where there was a disagreement between the treating physician and the family, and would recommend that the hospital refer the case to an appropriate court or child protective services agency if the Committee disagreed with the family's refusal to consent to treatment. 45 C.F.R. 84.55(f)(3)(ii). Finally, the Committee would conduct a retrospective record review of cases in which treatment had been withdrawn or

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[3] The ICRC would be composed of a practicing physician, a practicing nurse, a hospital administrator, a representative of the legal profession, a representative of a disability group or a disability expert, a lay community member, and a member of the hospital's organized medical staff, who would serve as chairman. 45 C.F.R. 84.55(f)(2).

withheld, in order to determine whether such instances were consistent with the hospital's policies. 45 C.F.R. 84.55(f)(1)(ii).[4]

ii. Consistent with the policy of involving the States in the cooperative effort as well, the regulations require each state child protective services agency that receives federal financial assistance to establish methods of administration and procedures to assure that it utilizes its full authority pursuant to state law to prevent unlawful medical neglect of handicapped infants. 45 C.F.R. 84.55(c) (J.A. 114-115). These provisions implement the state agencies' independent legal obligation under Section 504 to provide their protective services in a nondiscriminatory manner. "For those complaints that are expeditiously and effectively investigated and pursued by State agencies, the Secretary anticipates that additional federal efforts will often be unnecessary." 48 Fed. Reg. 30849 (1983).[5]

iii. The new regulations also make minor adjustments in HHS's preexisting procedures (see 45 C.F.R. Pt. 84) to address certain aspects of the investigation of complaints under Section 504 in this setting. Thus, the regulations provide for expedited access to records and facilities of the recipient hospital for investigative purposes when "necessary to pro-

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[4] In Section 124(b) of the Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1754, Congress similarly directed the Secretary to promulgate model guidelines to encourage the establishment of ICRCs within health care facilities. See page 44, *infra*. Those additional guidelines were promulgated by the Secretary on April 15, 1985. See 50 Fed. Reg. 14893.

[5] The methods and procedures must include a requirement that health care providers report instances of unlawful medical neglect of handicapped infants; provisions for the state agency to review and investigate such reports; procedures for affording child protective services to medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the furnishing of necessary nourishment and medical treatment; and notification to HHS of each report of suspected medical neglect of an infant solely because of his handicap. 45 C.F.R. 84.55(c). The requirement that the state agency establish methods of administration and procedures to prevent discrimination was modeled after a similar requirement (see 45 C.F.R. 80.4(b)) applicable to state programs under Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d *et seq.* 49 Fed. Reg. 1627 (J.A. 29).

tect the life or health of a handicapped individual." 45 C.F.R. 84.55(d) (J.A. 115). In addition, an appendix to the regulations sets forth guidelines for HHS investigations of reports of unlawful withholding of medical treatment. Those guidelines require consultation with the hospital's Infant Care Review Committee (if the hospital has one) and efforts to insure that investigations are conducted promptly and with the least disruption possible. 45 C.F.R. Pt. 84, App. C para. (b) (J.A. 123-126).

iv. Finally, the regulations require recipient hospitals to post an appropriate notice, visible to nurses and other medical professionals, that: (1) states that Section 504 prohibits the withholding of nourishment and medically beneficial treatment from handicapped infants based solely on their present or anticipated mental or physical impairments, and (2) identifies the designated hospital official, the appropriate child protective services agency, and the HHS office that may be contacted to obtain further information or to report suspected noncompliance. 45 C.F.R. 84.55(b) (J.A. 112-114).[6]

B. The Proceedings In This Case

1. On April 6, 1983, the American Hospital Association, the Hospital Association of New York State, and Strong

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In Section 122(3) of the Child Abuse Amendments of 1984 (98 Stat. 1752), Congress amended 42 U.S.C. 5103(b)(2) to require state child protective services agencies, as a condition to receiving funds under the Child Abuse Prevention and Treatment Act, 42 U.S.C. 5101 *et seq.*, to have similar procedures in place to respond to instances of withholding of medically indicated treatment from disabled infants who have life-threatening conditions. See page 44, *infra*. HHS promulgated regulations to implement this provision on April 15, 1985. See 50 Fed. Reg. 14878. In doing so, HHS stated that if the Secretary's interpretation of Section 504 is sustained by this Court, she will take steps to forge an "effective interrelationship" between the regulations under Section 504 and those under the Child Abuse Amendments. See 50 Fed. Reg. 14885 (1985).

[6] HHS explained that the posting of notices is a "time honored and reasonable method for providing notice to concerned individuals with respect to civil rights protections now utilized under a variety of programs" (48 Fed. Reg. 30850 (1983)). HHS modified its original proposal to reduce the minimum size of the notice (to 5 x 7 inches) and to provide that it need not be visible to the public (49 Fed. Reg. 1625-1626 (J.A. 23-27)).

Memorial Hospital filed suit in the United States District Court for the Southern District of New York challenging the initial regulations that had been promulgated by the Secretary on March 7, 1983. See page 3, *supra*. The district court entered a temporary restraining order barring enforcement of those regulations in New York State. *American Hospital Ass'n* v. *Heckler*, No. 83 Civ. 2638-CLB (S.D.N.Y. Apr. 6, 1983). However, before the court could hold a hearing, the United States District Court for the District of Columbia declared the regulations invalid on APA grounds. See *American Academy of Pediatrics* v. *Heckler*, discussed at page 3, *supra*. On March 12, 1984, after the Secretary promulgated the new regulations at issue here, the plaintiffs filed an amended complaint challenging those regulations as beyond the Secretary's authority under Section 504 (J.A. 2, 151-159). On the same date, a second suit was filed by the American Medical Association, the American Hospital Association, and others challenging the same regulations (J.A. 5, 129-150). The two suits were consolidated in the district court.

The district court thereafter held that the regulations are beyond the Secretary's statutory authority under Section 504 (Pet. App. 48a-49a), concluding that this case was controlled by the Second Circuit's decision in *United States* v. *University Hospital*, 729 F. 2d 144 (1984) (Pet. App. 4a-47a), discussed at pages 9-11, *infra*. The district court's final judgment permanently enjoins the Secretary from any further implementation of the regulations and from taking any other action under Section 504 to investigate or regulate treatment decisions involving impaired newborn infants in any program receiving federal financial assistance (Pet. App. 50a-52a).

The court of appeals summarily affirmed the district court's judgment on the basis of the court of appeals' prior decision in *University Hospital* (Pet. App. 1a-3a).

2. a. In *University Hospital*, which both the district court and court of appeals regarded as controlling in this case, a divided panel of the Second Circuit held that Section 504 is wholly inapplicable to the withholding of medical treatment from handicapped infants. The court therefore ruled that the government was not entitled under HHS's general

Section 504 regulations (45 C.F.R. 80.6(c), 84.61) to review the hospital's records in order to investigate alleged noncompliance with Section 504 in connection with the withholding of treatment from a particular handicapped infant, Baby Jane Doe.

The court of appeals in *University Hospital* assumed, without deciding, that the hospital's receipt of Medicare and Medicaid funds constituted the receipt of "Federal financial assistance" that triggered the application of Section 504 (Pet. App. 16a-18a), and it found that Baby Jane Doe was a "handicapped individual" for purposes of Section 504 (*id.* at 26a-28a). But the majority held that Baby Jane Doe was neither "otherwise qualified" for the hospital's services nor "subjected to discrimination" within the meaning of Section 504 (*id.* at 28a-39a). It believed that "the phrase 'otherwise qualified' is geared toward relatively static programs or activities such as education, employment, and transportation systems" (Pet. App. 30a (citations omitted)). "As a result," the court reasoned, "the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning" (*ibid.*). Nor, in the court's view, could the child be considered to be "subjected to discrimination," because "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory' " (*ibid.*).

The court of appeals acknowledged that Congress intended Section 504 to apply to the delivery of "health services" (Pet. App. 33a-35a, quoting S. Rep. 93-1297, 93d Cong., 2d Sess. 38 (1974)). But in its view that intent was not controlling because the legislative history did not contain a specific reference to medical treatment decisions (Pet. App. 31a-38a). The court also acknowledged that HHS's implementing regulations promulgated in 1977 likewise apply to the delivery of health services and that those regulations specifically state that Section 504 prohibits a health care provider from refusing to treat a person because of his handicap (*id.* at 19a-20a, citing 45 C.F.R. 84.52 and Pt. 84, App. A para. 36). But the court nevertheless declined to attach significant weight to the Secretary's interpretation of Section

504 because, in its view, the regulatory history was "inconclusive" (*id.* at 25a; see generally *id.* at 18a-25a). Finally, the court believed that to require a hospital to petition a state court or to take other steps where the parents have withheld consent to necessary treatment for a handicapped infant would impose an impermissible "affirmative action" burden on the hospital (*id.* at 39a).

b. Judge Winter dissented (Pet. App. 42a-47a). He concluded that because Congress explicitly patterned Section 504 after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d *et seq.*, which prohibits discrimination on the basis of race in federally assisted programs, Congress had determined that, "so far as the administration of federal financial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race" (Pet. App. 43a-44a). Judge Winter stressed that the government has never taken the position that it is entitled to override a medical judgment; "[i]ts position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment" (*id.* at 44a). Based on the statutorily mandated analogy to racial discrimination, Judge Winter found the logic of the government's position to be "about as flawless as a legal argument can be" (*ibid.*):

> A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So, too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. Finally, once the legislative analogy to race is acknowledged, the intrusion on state authority becomes insignificant.

SUMMARY OF ARGUMENT

A. Section 504 of the Rehabilitation Act of 1973 provides that "[n]o otherwise qualified handicapped individual * * * shall, solely by reason of his handicap, * * * be denied

the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance * * * ." This language, which is patterned after Title VI of the Civil Rights Act of 1964 and Title IX of the Education Amendments of 1972, clearly prohibits the withholding of nourishment or necessary medical treatment from a handicapped infant, solely by reason of his handicap, in a federally assisted health services program.

The court of appeals acknowledged that a physically or mentally impaired infant is a "handicapped individual" within the meaning of Section 504. That term is defined broadly to include "*any* person"—without limitation based on the person's age—who has a physical or mental impairment that "substantially limits one or more of such person's major life activities" or who is "regarded as having such an impairment." 29 U.S.C. 706(7) (B). The infants who are the subject of the regulations and interpretative guidelines promulgated by the Secretary in 1984 have impairments that substantially limit their major life activities and are regarded by others as having such impairments. Section 504 likewise applies to "*any* program" that receives federal financial assistance, a phrase that plainly encompasses programs for the delivery of health services. When Congress intended exceptions to the coverage of Section 504—or to the coverage of the parallel prohibitions in Title VI and Title IX—it expressly so provided. The absence of any such exception in Section 504 for health care programs or for handicapped infants in such programs reinforces the conclusion that Section 504 applies in this setting.

There also is no basis for excluding the infants involved from the protection of Section 504 on the ground that they are not "otherwise qualified" to receive treatment from any federally assisted health services program. If a hospital would, as a general matter, treat the malady from which the handicapped infant suffers and is able to do so, the infant is "otherwise qualified" to receive services from that provider.

The only additional condition a hospital ordinarily would impose on the furnishing of such treatment is that the treatment be medically indicated in the circumstances of the particular patient's condition. But if an infant's handicapping

condition (*e.g.*, Down's Syndrome) would not prevent him from benefiting from a particular course of treatment (*e.g.*, surgery to repair a blocked esophagus), the infant has satisfied this requirement as well and therefore is "otherwise qualified" for the specific treatment. If, in those circumstances, a hospital nevertheless refused to furnish the treatment to a handicapped infant, even though it would furnish the treatment to a nonhandicapped child, the infant has, "solely by reason of his handicap," been "denied the benefits of" and been "subjected to discrimination under" the federally assisted program. Similarly, where the parents have withheld their consent to medically indicated treatment, if the hospital refused to notify the state child protective services agency or to petition a court for an order directing the treatment—even though the hospital would take such measures in the case of a nonhandicapped child—the handicapped infant has been denied the benefits of and been subjected to discrimination under the hospital's federally assisted program.

B. Each stage of the legislative history and administrative implementation of Section 504 firmly supports the plain meaning of the statutory text. As an initial matter, because Section 504 was patterned after Title VI of the Civil Rights Act of 1964, it is significant that one of the principal areas in which Title VI was intended to prevent discrimination was in the delivery of adequate health services, including those furnished to infants. Although there were only limited debates on Section 504 itself when it was enacted in 1973, the statements by its sponsors, Senator Humphrey and Representative Vanik, emphasized that handicapped infants have a right to live and to receive health care.

In 1974, Congress amended the definition of the term "handicapped individual" to assure that Section 504 would be given a broad coverage. The legislative history of those amendments makes clear that Congress intended Section 504 to apply to health services programs, that discrimination on the basis of handicap is to be regarded as similar to discrimination on the basis of race (which indisputably would be an impermissible ground on which to deny necessary medical treatment to an infant), and that the Secretary would promulgate regulations to implement Section 504. It is

significant as well that in 1974, Congress expanded the coverage of another statutory provision that specifically prohibits discrimination in admissions and treatment by federally assisted hospitals on the basis of one type of handicap (alcoholism). See 42 U.S.C. (Supp. I) 290dd-2(a). In so doing, Congress expressly rejected the position of respondent American Hospital Association that such matters should be left exclusively to medical professionals and that there is no role for federal law in prohibiting discrimination in the furnishing of medical treatment under federally assisted programs.

Consistent with this background, the comprehensive regulations promulgated by the Secretary in 1977 made clear that Section 504 applies to federally assisted health services programs and prohibits a provider of such services from refusing to treat a person's medical condition solely because the person has a handicap. The Secretary recognized that in this respect Section 504 is consistent with the statutes that already prohibited a federally assisted hospital from discriminating against alcoholics and drug addicts in admissions and treatment. Congress in turn ratified this interpretation of Section 504 when it again amended the Rehabilitation Act in 1978. The 1984 regulations and interpretative guidelines merely elaborate upon and implement those established principles in the particular context of the withholding of necessary medical care from a handicapped infant.

ARGUMENT

SECTION 504 OF THE REHABILITATION ACT OF 1973 PROHIBITS THE WITHHOLDING OF NOURISHMENT OR MEDICALLY BENEFICIAL TREATMENT FROM A HANDICAPPED INFANT, SOLELY BECAUSE OF HIS HANDICAP, IN ANY PROGRAM OR ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE

Section 504 of the Rehabilitation Act of 1973 mandates a "broad government policy that programs receiving Federal

financial assistance shall be operated without discrimination on the basis of handicap." S. Rep. 93-1297, 93d Cong., 2d Sess. 39 (1974). It was enacted to prevent discrimination against "all handicapped individuals" under "any" federally assisted program, specifically including those providing for the delivery of "health services" (*id.* at 38). Consistent with this congressional intent, the comprehensive regulations promulgated by the Secretary in 1977 made clear that Section 504 applies to federally assisted health care programs and that it prohibits a provider from refusing to treat a handicapped person solely because of his handicap. The additional regulations and interpretative guidelines promulgated by the Secretary in 1984, which are at issue in this case, merely elaborate upon and implement that settled administrative interpretation in the particular context of a health care provider's withholding of nourishment or medically beneficial treatment from a handicapped infant solely because of his handicap.

The Secretary stressed that the interpretative guidelines contained in the 1984 regulations were intended to be flexible and that the actual application of Section 504 in this setting would have to be addressed on a case-by-case basis, with a sensitive regard for the circumstances presented. The court of appeals has now foreclosed that process by invalidating the regulations and interpretative guidelines on their face and issuing a nationwide injunction, without waiting for the Secretary to consider their application in the circumstances of any particular instance of the withholding of medical care. The court's premise was that Section 504 does not apply to this entire category of cases, no matter what the circumstances. Thus, to use one of the specific examples cited in the interpretative guidelines (see note 2, *supra*), Section 504 does not, in the court of appeals' view, prohibit a federally assisted hospital from withholding life-saving surgery to correct an intestinal obstruction in an infant with Down's Syndrome—even if the hospital would not hesitate to perform the same surgery for a normal child and the hospital's failure to perform the surgery is based solely upon the anticipated mental retardation of the infant and therefore solely upon his handicap.

The implied exception the court of appeals fashioned from the broad protections of Section 504 is contrary to the statute's text, legislative history, and consistent administrative interpretation. That exception also is contrary to the overriding purpose of Section 504 to assure "evenhanded treatment" of handicapped individuals and to afford them the opportunity "to participate in and benefit from programs receiving federal assistance." *Alexander* v. *Choate,* No. 83-727 (Jan. 9, 1985), slip op. 16.

The regulations and guidelines the court of appeals invalidated do not intrude the Secretary into complex medical judgments made by health care professionals. They embody a simple principle and impose a single duty: that a provider base its decision regarding whether or how to treat a handicapped infant on a bona fide medical judgment regarding the potential risks and benefits to the infant, and not on the mere fact that the infant is handicapped and may remain so after the treatment. When Congress enacted Title VI of the Civil Rights Act of 1964, it deemed a child's race, color, or national origin to be an impermissible basis on which to deny him needed medical treatment under a federally assisted program. In Section 504, Congress likewise deemed a child's handicap to be an impermissible basis on which to deny treatment, unless the handicap itself renders the treatment contraindicated as a medical matter. In concluding otherwise, the court of appeals has excluded from the coverage of Section 504 an entire category of individuals who—by reason of their infancy, their handicaps, and their life-threatening circumstances—are especially in need of its protection

A. THE LANGUAGE OF SECTION 504 CLEARLY PROHIBITS A FEDERALLY ASSISTED HOSPITAL FROM WITHHOLDING NOURISHMENT OR MEDICAL TREATMENT FROM A HANDICAPPED INFANT SOLELY BECAUSE OF HIS HANDICAP

The starting point of analysis of course must be the language of Section 504 itself, for " 'we assume "that the legislative purpose is expressed by the ordinary meaning of

the words used." ' " *Kosak* v. *United States,* No. 82-618 (Mar. 21, 1984), slip op. 5 (quoting *American Tobacco Co.* v. *Patterson,* 456 U.S. 63, 68 (1982), and *Richards* v. *United States,* 369 U.S. 1, 9 (1962)). See *Consolidated Rail Corp.* v. *Darrone,* No. 82-862 (Feb. 28, 1984), slip op. 7-9. Contrary to the court of appeals' view (Pet. App. 28a-31a), the language of the statutory prohibition clearly supports the established interpretation set forth in the 1977 regulations and elaborated upon in the 1984 regulations at issue here.

Section 504 provides in relevant part:

> No otherwise qualified handicapped individual in the United States * * * shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance * * *.

Before parsing this language, it is appropriate to recall the principles that govern its construction.

The language of Section 504 "cannot be read in isolation from its history and purposes." *Darrone,* slip op. 8 n.13. "Section 504 was patterned after, and is almost identical to, the antidiscrimination language of section 601 of the Civil Rights Act of 1964, 42 U.S.C. 2000d-1 (relating to race, color, or national origin) and section 901 of the Education Amendments of 1972, 42 U.S.C. 1683 (relating to sex)." *Alexander* v. *Choate,* slip op. 5 n.7 (quoting S. Rep. 93-1297, *supra,* at 39). The first of these provisions, Title VI, is founded on the principle " 'that funds of the United States are not used to support racial discrimination' but 'are spent in accordance with the Constitution and the moral sense of the Nation.' " *Darrone,* slip op. 8 n.13 (quoting 110 Cong. Rec. 6544 (1964) (remarks of Sen. Humphrey)). The language Congress employed to state this principle of "[s]imple justice"[7] is "majestic in its sweep" (*Regents of the University of California* v. *Bakke,* 438 U.S. 265, 284 (1978) (opinion of Powell, J.)). And the Court observed with respect to the same language in Title

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[7] *Lau* v. *Nichols,* 414 U.S. 563, 569 (1974) (quoting 110 Cong. Rec. 6543 (1964) (remarks of Sen. Humphrey), and 109 Cong. Reg. 11161 (1963) (President Kennedy's Message to Congress)).

IX that " 'if we are to give [the statutory prohibition] the scope that its origins dictate, we must accord it a sweep as broad as its language.' " *North Haven Board of Education* v. *Bell*, 456 U.S. 512, 521 (1982) (quoting *United States* v. *Price*, 383 U.S. 787, 801 (1966)). The Court therefore has been "reluctant to read into [the statutory language] a limitation not apparent on its face." *Grove City College* v. *Bell*, No. 82-792 (Feb, 28, 1984), slip op. 8.

These principles also govern the construction of the parallel language in Section 504. See, *e.g.*, *Darrone*, slip op. 6-10 & n.13; *Alexander* v. *Choate*, slip op. 5 n.7. As we explain below, an analysis of each of the operative phrases in the statutory text demonstrates that a provider's withholding (in a federally assisted program or activity) of nourishment, medically beneficial treatment, or related assistance from a handicapped infant solely because of his handicap falls squarely within the scope of Section 504. This language should be given its plain meaning, consistent with the "national commitment to eliminate the 'glaring neglect' of the handicapped" (*Alexander* v. *Choate*, slip op. 8 (quoting 118 Cong. Rec. 526 (1972) (remarks of Sen. Percy)).

1. "Handicapped Individual"

The court of appeals in *University Hospital* correctly recognized that an impaired newborn child is a "handicapped individual" for purposes of Section 504. See Pet. App. 26a-28a. The directive that "[n]o * * * handicapped individual" be subjected to discrimination manifests in itself an intent to give the statute an all-inclusive coverage, without regard to the individual's age. Compare *North Haven*, 456 U.S. at 520. See *Smith* v. *Robinson*, No. 82-2120 (July 5, 1984), slip op. 23 ("§504 protects handicapped persons of all ages"). Moreover, the term "handicapped individual" is defined in broad terms to mean "*any person* who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C. 706(7)(B) (emphasis added). There can be no doubt that the infants who are the subject of the concern that gave rise to the 1984 regulations have "physical

or mental impairment[s]" within the meaning of clause (i) of this definition (see 45 C.F.R. 84.3(j)(2)(i)), and it is equally clear that those impairments substantially limit one or more of the infants' "major life activities" within the meaning of clause (i).[8] In addition, as the court of appeals observed (Pet. App. 27a), "it would defy common sense" to rule that the Baby Jane Doe involved in *University Hospital* was not at least "regarded" by others as having such an impairment, and thus handicapped within the meaning of clause (iii) of the statutory definition. See 45 C.F.R. 84.3(j)(2)(iv).

It also is significant that Congress expressly excluded one category of individuals from the statutory definition of the term "handicapped individual" quoted above. See 29 U.S.C. 706(7)(B) (excluding certain alcoholics and drug abusers), discussed at pages 42-43, *infra*. The absence of a similar exclusion for handicapped infants, either in general or in the specific context of the delivery of health services, further supports the conclusion that they are protected by the Act. *North Haven*, 456 U.S. at 521-522. Compare *Sure-Tan, Inc.* v. *NLRB*, No. 82-945 (June 25, 1984), slip op. 6-7.

2. "Program or Activity Receiving Federal Financial Assistance"

The language of Section 504 likewise does not suggest any exception that would permit discrimination against handicapped individuals under those federally assisted programs that furnish medical treatment, as distinguished, for example, from programs in the areas of employment or education. See *Alexander* v. *Choate*, *supra*. Section 504 contains no such "limiting language; rather, that section prohibits discrimination against the handicapped under '*any* program

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[8] HHS's general Section 504 regulations define the term "major life activities" to mean "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." 45 C.F.R. 84.3(j)(2)(ii). Although newborn infants cannot perform some of these functions, others of those mentioned (*e.g.*, seeing, hearing, breathing and learning) are capable of being performed by infants. Moreover, this listing expressly is not exclusive (it refers to functions "such as" those listed), and it therefore readily embraces any functions or activities that are comparably "major" in the life of an infant.

or activity receiving Federal financial assistance.' " *Darrone*, slip op. 7 (emphasis added by the Court).[9]

By contrast, in Title IX of the Education Amendments of 1972, Congress included a number of exceptions for circumstances in which it chose not to insist that the institution refrain from basing decisions specifically on the otherwise prohibited factor of the sex of the individual. 29 U.S.C. 1981(a)(1)-(9). See *North Haven*, 456 U.S. at 514-515 n.1, 521-522; see also 42 U.S.C. 2000d-3. Because Section 504 was patterned after Title IX and was enacted only a year later, the fact that Congress did not include any similar exceptions in Section 504 further reinforces the conclusion that Congress did not intend to leave federally assisted hospitals free to deny medically necessary treatment solely on the basis of the statutorily prohibited factor of the individual's handicap.

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[9] No question is presented in this case with regard to either the types of payments to a hospital that constitute federal financial assistance or the scope of the "program or activity" receiving such assistance. Compare *Darrone*, slip op. 11-12; *North Haven*, 456 U.S. at 540. The district court in *University Hospital* held that the hospital's receipt of payments for the furnishing of medical treatment under the Medicaid and Medicare Programs (42 U.S.C. (& Supp. I) 1395 *et seq.*; 42 U.S.C. 1396 *et seq.*) constituted the receipt of "Federal financial assistance" that triggered the application of Section 504, and that Section 504 applied whether or not Baby Jane Doe herself was a beneficiary under either program. *United States* v. *University Hospital*, 575 F. Supp. 607, 612-613 (E.D. N.Y. 1983). Compare *Grove City*, slip op. 15 n.21. This holding is consistent with HHS's longstanding position (see 45 C.F.R. Pt. 84, App. A paras. 1 and 2) and with the only court of appeals decision that has extensively considered the evidence of congressional intent. See *United States* v. *Baylor University Medical Center*, 736 F.2d 1039, 1042-1049 (5th Cir. 1984), cert. denied, No. 84-525 (Jan. 21, 1985).

The court of appeals in *University Hospital* declined to resolve this question. It assumed for purposes of its decision that the hospital's actions pertaining to Baby Jane Doe were under a program or activity receiving federal financial assistance by virtue of the hospital's receipt of Medicare and Medicaid funds (Pet. App. 16a-18a), but it held that Section 504 does not in any event address the question of discrimination in the medical treatment of handicapped infants (*id.* at 18a-41a). The district court and court of appeals in the instant case entered judgment in favor of respondents on the basis of that holding in *University Hospital* (*id.* at 2a-3a, 50a-51a), and they therefore likewise had no occasion to consider whether Medicare or Medicaid payments constitute "Federal financial assistance" and, if so, what the scope of the assisted "program or activity" should be.

3. "Otherwise Qualified"

Nor is there any basis for excluding the entire category of handicapped infants from the coverage of Section 504 on the ground that they are not "otherwise qualified" to receive nourishment and medically indicated treatment under federally assisted health care programs. This Court stated in *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979), that the plain meaning of the term "otherwise qualified handicapped individual" as used in Section 504 is "one who is able to meet all of a program's requirements in spite of his handicap." The Court's reasoning in that case further supports the interpretation of Section 504 set forth in the Secretary's 1984 regulations.

a. In *Davis*, a deaf person was unable to meet the generally applicable physical requirements for admission to the community college's associate degree nursing program because the ability to understand speech without reliance on lipreading was necessary for patient safety during the clinical phase of the program. 442 U.S. at 401-402, 407, 409-410, 413 n.12. See *Alexander* v. *Choate*, slip op. 12-13. The Court noted that substantial modifications of the college's nursing program would have been required in order to accommodate the limitations imposed by the applicant's hearing impairment, and it held that there "was no violation of § 504 when [the college] concluded that [she] did not qualify for admission to its program." 442 U.S. at 414. The Court explained that "[n]othing in the language or history of § 504 reflects an intention to limit the freedom of an educational institution to require reasonable physical qualifications for admission to [its] program" (442 U.S. at 414), but it made clear at the same time that "mere possession of a handicap is not a permissible

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In any event, the regulations and interpretative guidelines respondents challenge in this suit (45 C.F.R. 84.55 and Pt. 84, App. C) do not address the question of what constitutes a program or activity receiving federal financial assistance for purposes of Section 504; they simply set forth a hospital's duties where it has such a program or activity. The question of coverage therefore can appropriately be addressed only in the context of the application of Section 504 to a particular hospital. The governing legal standard is, of course, that described and applied by this Court in *Grove City*, slip op. 14-17.

ground for assuming an inability to function in a particular context" (*id.* at 405).

Davis establishes that whether a handicapped person is "otherwise qualified" must be determined by reference to the reasonable and bona fide standards and qualifications of general applicability that serve the operational needs of the particular federally assisted program or activity. That interpretation is strongly supported by the legislative history[10] and is embodied in the regulations promulgated by the Secretary in 1977, as this Court recognized in *Davis* (see 442 U.S. at 406, quoting 45 C.F.R. 84.3(k)(3); see also 45 C.F.R. 84.3(k)(1)-(5) and Pt. 84, App. A para. 5). In the context of a program furnishing health services, for example, the 1977 regulations state that a qualified handicapped person is "a handicapped person who meets the essential eligibility requirements for the receipt of such services." 45 C.F.R. 84.3(k)(4).

There has been no suggestion in this case that the handicapped infants who are the subject of the regulations and guidelines promulgated in 1984 categorically fail to satisfy the generally applicable eligibility requirements of all federally assisted hospitals and that no such infant therefore is "otherwise qualified" to receive the benefits of the medical services furnished by any federally assisted hospital. Such an

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[10] As this Court observed in *Alexander* v. *Choate* (slip op. 7-8 n.13), Section 504 had its origins in companion bills introduced by Representative Vanik and Senators Humphrey and Percy in the 92d Congress. H.R. 12154, 92d Cong., 1st Sess., 117 Cong. Rec. 45945 (1971); S. 3044, 92d Cong., 2d Sess., 118 Cong. Rec. 525-526 (1972). Those bills would have amended Title VI to bar discrimination against a person on the basis of a handicap "unless lack of such physical or mental handicap is a bona fide qualification reasonably necessary to the normal operation of such program or activity." 118 Cong. Rec. 526 (1972). See also *id.* at 2999 (remarks of Rep. Vanik). Section 504 embodies the intent of this predecessor bill. *Alexander* v. *Choate*, slip op. 8 n.15; see 119 Cong. Rec. 6145 (1973) (remarks of Sen. Humphrey); *id.* at 7114 (remarks of Rep. Vanik). The phrase "otherwise qualified" in Section 504 therefore should be understood to refer to a qualification reasonably necessary to the operation of the federally assisted program. See also 124 Cong. Rec. 30322-30325 (1978) (debate on 1978 amendment to 29 U.S.C. 706(7), discussed at pages 42-43, *infra*); 124 Cong. Rec. 37509-37510 (remarks of Sen. Williams).

assertion would be untenable. To be sure, there are some special purpose hospitals or other providers that do not treat certain categories of patients or types of conditions. Section 504 would not require such a provider to treat an infant, simply because he is handicapped, for a condition the provider otherwise would not treat under a bona fide policy of this kind. See page 40, *infra;* compare *Alexander* v. *Choate,* slip op. 14-21. But that limited rationale plainly has no application to a general hospital or other provider that does admit and treat patients with the types of conditions for which the handicapped infant requires attention. Indeed, the question whether a handicapped infant is "otherwise qualified" to receive medical services within the meaning of Section 504 typically arises with respect to infants who already are patients in a hospital.

b. Of course, even where a hospital or other provider does afford a particular type of treatment as a general matter, a further condition typically imposed on the ability of any given person to receive that treatment is that it be medically indicated in his particular cirumstances. A hospital ordinarily does not perform surgery or afford other treatment to any patient, handicapped or not, if he will not benefit medically from it. Nothing in Section 504 requires a hospital to abandon that neutral principle in the case of handicapped infants. But if the limitations stemming from the infant's handicapping condition (*e.g.,* Down's Syndrome) would not prevent him from benefiting from a particular course of treatment (*e.g.,* corrective surgery to repair a blocked esophagus), the infant has satisfied this requirement as well.[11] He therefore must be deemed "otherwise qualified" to receive the treatment. Cf. *Davis,* 442 U.S. at 401-402, 409-410: *Alexander* v. *Choate,* slip op. 12-13.

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[11] Cf. 42 U.S.C. (Supp. I) 1395y(a)(1)(A) (payments may be made under the Medicare Program for services that are "reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member"); 42 U.S.C. 1396 (Medicaid appropriations are authorized for "necessary medical services" and for "rehabilitation and other services to help families and individuals attain or retain capability for independence or self-care"); *Beal* v. *Doe,* 432 U.S. 438, 445-446 (1977).

The interpretative guidelines promulgated by the Secretary in 1984 are based on this construction of the term "otherwise qualified."[12] Those guidelines state that with respect to programs or activities receiving federal financial assistance, "health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment." 45 C.F.R. Pt. 84, App. C para. (a)(1) (J.A. 122).[13] A denial of treatment in those circumstances would be based precisely on the existence of the infant's handicap, standing alone, not on the fact that the handicapping condition results in limitations or has other manifestations which in turn cause the individual to fail to meet bona fide qualifications established under the federally assisted program, as in *Davis*. This Court made clear in *Davis* that "mere possession of a handicap is not a permissible ground for assuming an inability to function in a particular context." 442 U.S. at 405. So, too, mere possession of a handicap – as distinguished from any consequences of the handicapping condition that render medical treatment contraindicated – is not a permissible ground for assuming that an infant is unable to benefit medically from treatment. That rationale would relegitimize the very "societal neglect" of handicapped persons that Congress sought to eliminate through the passage of Section 504. See *Alexander* v. *Choate*, slip op. 8 (quoting 119 Cong. Rec. 5883 (1973) (remarks of Sen. Cranston)).

c. The court of appeals majority in *University Hospital* did not appear to take issue with the general proposition that the term "otherwise qualified" in Section 504 refers to

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[12] See 49 Fed. Reg. 1636 (J.A. 60):

> If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

[13] "Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant." *Id.* para. (a)(2) (J.A. 122).

reasonable and neutral standards of eligibility under the particular program and that a person's handicapping condition ordinarily may be the basis for denying him the benefits of that program only if its effects or manifestations render him unqualified under such standards. See Pet. App. 28a-30a.[14] But the court of appeals found that proposition inapplicable in the present setting. It believed that the term "otherwise qualified" is "geared toward relatively static programs or activities such as education, employment, and transportation systems," and cannot readily be applied in what the court labeled the "comparatively fluid context" of medical treatment decisions without "distorting its plain meaning" (Pet. App. 30a). It is the majority in *University Hospital* that distorted the plain meaning of Section 504, because the proffered distinction between "static" and "fluid" contexts finds no support whatever in the statutory language. That distinction is just another way of arguing that discrimination in programs for the delivery of medical care should be excluded from the coverage of Section 504. As we have shown, however, Section 504 broadly prohibits discrimination in "*any* program or activity receiving Federal financial assistance" (emphasis added); see *Darrone*, slip op. 7.

By its use of the term "fluid," the court of appeals apparently had in mind that a handicapped infant's need for medical treatment may vary with changes in the child's physical condition. But that factor is not in itself logically determinative of whether at any given time an individual is "qualified" for a particular medical procedure or course of treatment. Indeed, in some circumstances, it may simply underscore his pressing need for treatment. Insofar as the term "otherwise qualified" is concerned, the guiding principle in all circumstances, fluid or not, is whether a particular course of treatment would be

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[14] The decisions upon which the court of appeals relied, in addition to this Court's decision in *Davis*, all endorse this view of the term "otherwise qualified" in Section 504. See *Dopico* v. *Goldschmidt*, 687 F.2d 644, 652-653 (2d Cir. 1982); *Doe* v. *New York University*, 666 F.2d 761, 775-776 (2d Cir. 1981); *Prewitt* v. *United States Postal Service*, 662 F.2d 292 (5th Cir. 1981); *Simon* v. *St. Louis County*, 656 F.2d 316, 320-321 (8th Cir. 1981), cert. denied, 455 U.S. 976 (1982).

medically beneficial for the child. That presumably is the sort of judgment that health care professionals are accustomed to making on behalf of all of their patients. Section 504 and the implementing regulations and guidelines at issue here simply require that those professionals also make such a medical judgment on behalf of their patients who are handicapped infants, and not rest their decisions and deny beneficial care on the basis of the bare presence of the infant's handicapping condition. Compare *Youngberg* v. *Romeo*, 457 U.S. 307, 323 (1982). Where the infant's condition is "fluid," that factor may justify additional deference to a physician's professional medical judgment in choosing among alternatives. But it does not render Section 504 wholly inapplicable.[15]

4. "Denied Benefits" or "Subjected to Discrimination" On the Basis of Handicap

Against the background of the foregoing discussion, the final element of the prohibition in Section 504—the element of discrimination—requires little discussion. If, in a federally assisted program, a hospital has refused to furnish an infant who has a handicap (*e.g.*, Down's Syndrome) with treatment that would be medically beneficial (*e.g.*, surgery to correct a blocked esophagus) and that would be performed for a child who is not handicapped, the infant quite clearly has, "solely

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[15] The fact that some physical conditions may fluctuate could not in any event support a wholesale exemption from Section 504 for *all* decisions relating to medical treatment, as the court of appeals appeared to hold. There is nothing "fluid" about the need of a child with Down's Syndrome for corrective esophagal surgery to enable him to receive nourishment. By the same token, programs and activities other than those that involve the furnishing of health services do not necessarily address only "static" situations, as the majority in *University Hospital* seemed to believe. For example, decisions that affect a handicapped child might be made every day in a federally assisted educational or physical rehabilitation program, and adjustments might have to be made in such a program to take into account fluctuations or developments in the child's physical or mental condition. The novel distinction advanced by the majority in *University Hospital* therefore has no logical (much less legal) basis, and its adoption would substantially undermine the effort to develop manageable standards in the administration and enforcement of Section 504. Cf. *Alexander* v. *Choate*, slip op. 10-11.

by reason of his handicap," been "denied the benefits of" and been "subjected to discrimination under" the federally assisted program. Thus, contrary to the court of appeals' view, the language of Section 504 firmly supports the regulations and interpretative guidelines respondents have challenged in this suit.

The guidelines also address the question of the hospital's responsibilities under Section 504 when the parents have refused to consent to medically beneficial treatment for their child. The Secretary determined when she promulgated the guidelines that most hospitals have established procedures to petition a court to order necessary medical care for a child if the parents do not consent and that health care professionals generally are required by state law to report cases of medical neglect to the appropriate state agency (49 Fed. Reg. 1631 (J.A. 43-44)). These special services and protections furnished to children who have been taken into a hospital's care under a federally assisted program are no less a part of that program than is the furnishing of the medical treatment itself. Accordingly, if the hospital refuses to take such protective measures on behalf of a handicapped infant, but would do so on behalf of a nonhandicapped child, the handicapped infant has, "solely by reason of his handicap," been "denied the benefits of" and been "subjected to discrimination under" the federally assisted program. The relevant guideline therefore states that such conduct would violate Section 504. See 45 C.F.R. Pt. 84, App. C para. (a)(4) (J.A. 122).

The court of appeals believed that to require a hospital to take these steps where the parents have withheld consent "would impose a particularly onerous affirmative action burden upon the hospital," and thereby contravene this Court's decision in *Davis* (see Pet. App. 39a). This conclusion was based on a misinterpretation of *Davis*, a misunderstanding of the Secretary's position, and a gross exaggeration of the burden involved. In *Davis*, the court held that Section 504 did not obligate the college to make "substantial modifications" in its nursing program to accommodate the needs of a deaf student (442 U.S. at 413). See *Alexander* v. *Choate*, slip op. 13 n.20. The relevant guideline at issue here, however, requires a hospital to initiate steps to override a parental with-

holding of consent to life-saving treatment for a handicapped child only if the hospital would do so for a nonhandicapped child. Thus, Section 504, as applied to handicapped infants in this context, requires a hospital to follow, not to modify, its existing policies. It imposes no new "affirmative action" obligation on a hospital within the meaning of *Davis*.

Nor can the requirement that the hospital take appropriate steps in such circumstances fairly be characterized as an "onerous" burden, especially when weighed against the consequences for the child. This much is demonstrated by the fact that hospitals commonly *do* take steps to assure treatment when, for example, religious convictions prohibit the parents from consenting to medical treatment or a necessary blood transfusion.[16] In fact, the hospital in the Bloomington Baby Doe case applied for such a court order. See note 1, *supra*. The hospital also might fulfill its obligation to afford evenhanded treatment to a handicapped child by notifying the state child protective services agency, which in turn could investigate the matter and seek any necessary court order. State law typically requires health care professionals to report cases of medical neglect,[17] and in Section 122(3) of the Child Abuse Amendments of 1984, Congress has now *required* the States, as a condition to receiving certain federal funds, to provide for prompt reporting by designated hospital officials of cases of suspected withholding of medically indicated treatment from disabled infants who have life-threatening conditions. See 50 Fed. Reg. 14888 (1985).

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[16] See, *e.g.*, *Jehovah's Witnesses in the State of Washington* v. *King County Hospital*, 278 F. Supp. 488 (W.D. Wash. 1967), aff'd, 390 U.S. 598 (1968); *Raleigh Fitkin-Paul Morgan Memorial Hospital* v. *Anderson*, 42 N.J. 421, 201 A.2d 537, cert. denied, 377 U.S. 985 (1964); *Application of Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979); *In re Sampson*, 37 A.D.2d 668, 323 N.Y.S.2d 253 (Sup. Ct. 1971), aff'd, 29 N.Y.2d 900, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972).

[17] See Smith, *Life and Death Decisions in the Nursery: Standards and Procedures for Withholding Lifesaving Treatment from Infants*, 27 N.Y.L. Sch. L. Rev. 1125, 1183 n.255 (1982); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 Stan. L. Rev. 213, 233-234 (1975).

B. THE LEGISLATIVE HISTORY AND CONSISTENT ADMINISTRATIVE CONSTRUCTION OF SECTION 504 STRONGLY SUPPORT THE PLAIN MEANING OF THE STATUTORY TEXT

As we have shown in Point A, the language of Section 504 clearly prohibits a federally assisted hospital program from denying a handicapped infant nourishment or medically beneficial treatment solely because of his handicap. "Absent a clearly expressed legislative intention to the contrary, that language must ordinarily be regarded as conclusive." *Consumer Product Safety Commission* v. *GTE Sylvania, Inc.*, 447 U.S. 102, 108 (1980). See also *CIA* v. *Sims*, No. 83-1075 (Apr. 16, 1985), slip op. 8-9. In this case, there is no indication whatever of a contrary legislative intention, much less one that is "clearly expressed."

In addition, Congress intended that the Secretary issue regulations implementing Section 504 and that she have "substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*, slip op. 16 n.24, citing S. Rep. 93-1297, *supra*, at 40-41, 56. See also *id.* at 19-20 & n.32; *Darrone*, slip op. 9-10 & nn.14-16; *Community Television* v. *Gottfried*, 459 U.S. 498, 511-512 (1983); *Davis*, 442 U.S. at 413. When Congress has entrusted the administration of a statute to an agency in this manner, a court "does not simply impose its own construction on the statute, as would be necessary in the absence of an administrative interpretation." *Chevron U.S.A. Inc.* v. *NRDC*, No. 82-1005 (June 25, 1984), slip op. 5. Instead, the question for the court is "whether the agency's answer is based on a permissible construction of the statute." *Id.* at 4-5. At the very least, the Secretary's interpretation of Section 504 in the present context is a permissible one. Indeed, as we now demonstrate, there is firm support for that interpretation at every stage in the evolution of Section 504—from its origins in Title VI of the Civil Rights Act of 1964 through its enactment, the subsequent amendment of its operative terms, and its administrative implementation.

1. Title VI of the Civil Rights Act of 1964

Section 504 was modeled after Title VI of the Civil Rights Act of 1964, and in fact the nondiscrimination principle it embodies was originally proposed by Representative Vanik and Senators Humphrey and Percy as an amendment to Title VI. *Alexander* v. *Choate,* slip op. 5 n. 7, 7-8 & n.13. See note 10, *supra.* The backdrop of Title VI against which Congress acted therefore is the starting point in ascertaining the meaning of Section 504.

As this Court recognized in *Bakke,* one of the principal purposes of Title VI was to eliminate discrimination in federally assisted programs for the delivery of health services. Two of the separate opinions in *Bakke* quote the statement by Representative Celler, Chairman of the House Judiciary Committee and floor manager of the bill, that Title VI "would offer assurance that hospitals financed by Federal money would not deny adequate care to Negroes."110 Cong. Rec. 1519 (1964) (quoted in 438 U.S. at 285 (opinion of Powell, J.), and 438 U.S. at 330 (opinion of Brennan, White, Marshall, and Blackmun, J.J.)). Similarly, Senator Humphrey stated that "[d]iscriminatory treatment of patients is obviously a discrimination against beneficiaries of the Hill-Burton Act [42 U.S.C. (1958 ed.) 291 *et seq.*]," and he observed that Title VI could be enforced "by requiring that hospitals receiving Federal construction grants under the Hill-Burton Act agree not to exclude or segregate patients, or otherwise discriminate in their treatment of patients, because of race, color or national origin." 110 Cong. Rec. 6546 (1964).

Representative McCulloch and others stated that "example after example is available which establishes that Negroes are denied equal treatment under the [Hill-Burton] Act," with the result that "the health standards of Negroes and, thereby, the Nation are impaired" (H.R. Rep. 914, 88th Cong., 1st Sess. Pt. 2 at 24 (1963) (additional views of Reps. McCulloch, et al.)). And Representative Ryan stated: "The denial of the best available medical care because of a patient's color is inconsistent with the most basic democratic principles. By passing title VI Congress will make clear its intention that this practice cease." 110 Cong. Rec. 2482 (1964).

Supporters of Title VI also repeatedly cited the Fourth Circuit's then-recent decision in *Simkins* v. *Moses H. Cone Memorial Hospital*, 323 F.2d 959 (1963), cert. denied, 376 U.S. 938 (1964), which held that the refusal to admit black patients to hospitals that received Hill-Burton funds violated the Constitution, and they stated that Title VI embodied the same principle of nondiscrimination. See *Bakke*, 438 U.S. at 332-333 (opinion of Brennan, White, Marshall & Blackmun, J.J.) (quoting 110 Cong Rec. 6544 (1964) (remarks of Sen. Humphrey)).[18] Senator Humphrey and others deplored the effect that those practices had on the persons who were denied treatment, quoting the Fourth Circuit's observation in *Moses H. Cone* that "[r]acial discrimination in medical facilities is at least partly responsible for the fact that in North Carolina the rate of Negro infant mortality is twice the rate for whites and maternal deaths are five times greater."[19]

Consistent with this congressional intent, the regulations promulgated by the Department of Health, Education, and Welfare to effectuate Title VI provided that "[i]n grant programs which support the provision of health * * * services, discrimination in the selection or eligibility of individuals to receive the services, and segregation or other discriminatory practices in the manner of providing them, are prohibited." 45 C.F.R. 80.5(a) (1966). The regulations also made clear that hospitals applying for federal financial assistance would be required to give assurances of nondiscrimination with respect to "admission or other treatment of individuals as * * * patients" (45 C.F.R. 80.4(d)(2) (1966)). Against this background, it is beyond question that Title VI prohibits a hospital from denying nourishment or medical treatment to an infant because of his race.

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[18] See also 110 Cong. Rec. 2467, 2468 (1964) (Rep. Celler); *id.* at 2595 (Rep. Donohue); *id.* at 6050 (Sen. Javits); *id.* at 6543, 6546 (Sen. Humphrey); *id.* at 6561 (Sen. Kuchel); *id.* at 7054, 7055, 7062 (Sen. Pastore); *id.* at 7065 (Sen. Ribicoff).

[19] 323 F.2d at 970 n.23 (quoted at 110 Cong. Rec. 6543 (1964) (remarks of Sen. Humphrey)). See also 110 Cong. Rec. 2468 (Rep. Celler); *id.* at 7054, 7055 (Sen. Pastore).

2. The Enactment of Section 504 in 1973

It was on the foundation of Title VI, just discussed, that Congress enacted Section 504 in 1973. When Congress incorporates the terms of a prior law into a later statute, it is presumed to know the scope, purposes, and administrative interpretation of the prior law and to intend that they be followed under the later enactment. *Cannon* v. *University of Chicago*, 441 U.S. 677, 694-698 (1979); *Lorillard* v. *Pons*, 434 U.S. 575, 580-581 (1978). Congress therefore must be presumed to have been aware in 1973 that one of the principal applications of Title VI was in the area of health services and that HEW's Title VI regulations prohibited a hospital from discriminating in the admission and treatment of patients and the selection of persons to receive services. Absent a contrary indication, it is reasonable to infer that Congress intended Section 504 to have a similar scope. That inference is all the more warranted because Senator Humphrey was a principal sponsor of both Section 504 and Title VI. Further, because handicapped persons often have a special need for medical care, it would be contrary to the entire thrust of the Rehabilitation Act to construe Section 504 to be inapplicable to the denial of necessary medical treatment solely because of an individual's handicap. Cf. *Darrone*, slip op. 7 n.12. Nothing in the legislative history suggests that Congress intended that anomalous result.

The Committee Reports on the various versions of the bill describe Section 504 only briefly and in general terms that in many instances merely paraphrase the statutory language.[20] Certainly nothing in these passages undermines the interpretation of Section 504 reflected in the guidelines promulgated by the Secretary in 1984. Because there were no substantial floor debates on Section 504 in 1973, the Court has concluded that "the intent with which Congressman Vanik and Senator Humphrey crafted the predecessor to § 504 is a

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[20] See S. Rep. 92-1135, 92d Cong., 2d Sess. 49, 77 (1972); H.R. Conf. Rep. 92-1581, 92d Cong., 2d Sess. 78 (1972); S. Rep. 93-48, 93d Cong., 1st Sess. 18, 53, 80 (1973); H.R. Rep. 93-42, 93d Cong., 1st Sess. 42 (1973); S. Rep. 93-318, 93d Cong., 1st Sess. 18, 50, 70 (1973); H.R. Rep. 93-244, 93d Cong., 1st Sess. 35 (1973).

primary signpost on the road toward interpreting the legislative history of § 504." *Alexander* v. *Choate,* slip op. 8 n.13. The tenor of their remarks strongly supports the Secretary's interpretation of Section 504 to prohibit a hospital from denying a handicapped child, solely because of his handicap, the medical treatment necessary to address a life-threatening condition.

Senator Humphrey described the predecessor bill broadly (118 Cong. 525-526 (1972) (emphasis added)):

> I am insisting that the civil rights of 40 million Americans now be affirmed and effectively guaranteed by Congress—our several million disabled war veterans, the 22 million people with a severe physically disabling condition, the one in every 10 Americans who has a mental condition requiring psychiatric treatment, the 6 million persons who are mentally retarded, the hundreds of thousands crippled by accidents and the destructive forces of poverty, *and the 100,000 babies born with defects each year.*
>
> *These people have the right to live,* to work to the best of their ability—to know the dignity to which every human being is entitled* * *.
>
> * * * *Every child*—gifted, normal, and handicapped—*has* a fundamental right to educational opportunity and *the right to health* * * *.

And Senator Humphrey later stated that the bill "responded to an awakening public interest in millions of handicapped children, youth, and adults who suffer the profound indignity and despair of isolation, discrimination, and maltreatment." *Id.* at 9495. Represenatative Vanik explained the bill in terms that likewise manifest a concern for the treatment of handicapped children.[21]

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[21] See 117 Cong. Rec. 45974 (1971) (emphasis added):

> I am today introducing legislation to provide equal treatment of the handicapped in all programs which receive Federal assistance.
>
> * * * * *
>
> The number of handicapped is growing daily. *Every year 100,000 babies are born with defects* that will force them to use crutches, braces, or wheelchairs for all of their lives.

3. The 1974 Amendament of the Definition of the Term "Handicapped Individual"

a. In 1974, Congress amended the definition of the term "handicapped individual" as used in Section 504 in order to assure that Section 504 would have a broad scope. As originally enacted in 1973, that definition referred to a handicap as a disability that hinders employment and can reasonably be expected to benefit from vocational rehabilitation services.[22] Congress concluded in 1974 that although this definition was appropriate for determining an individual's eligibility for vocational rehabilitation services under the Act, it was not apt for defining the coverage of Section 504, which was intended to prohibit discrimination against handicapped persons in all federally assisted programs, not merely those concerned with vocational rehabilitation. S. Rep. 93-1297, *supra*, at 37-38. Accordingly, Congress enacted a separate provision applicable to Section 504 that defines a handicapped individual as a person who has a physical or mental impairment that substantially limits one or more of his major life activities, or who has a record of or is regarded

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> The masses of the handicapped live and struggle among us, often shunted aside, hidden and ignored. How have we as a nation treated these fellow citizens?
>
> In this country we still have the snakepit mental institutions – institutions for confinement without treatment, where brutality and unexplained deaths are common * * *.

See also 119 Cong. Rec. 7114 (1973). Subsequently, in remarks immediately before the Rehabilitation Act passed the House in 1973, Representative Vanik expressed gratification that his antidiscrimination provision had been included in the bill. But he decried the deletion of certain programs that had been intended to aid handicapped children, and he did so in terms that touch on the question presented in this case (119 Cong. Rec. 18137 (1973)):

> In ancient Greece, in the city-state of Sparta, the people would take the handicapped newborn, and leave them to die of exposure on the mountainside. Are we guilty of the same type of gross neglect in this country?

See also *id.* at 24586 (Senator Taft) ("the most disgraceful barrier of all—discrimination").

[22] See Section 7 (6) of the Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 361, now codified at 29 U.S.C. 706(7)(A).

as having such an impairment. See pages 18-19, *supra*.[23] In a number of respects, the legislative history of this amendment supports the Secretary's interpretation of Section 504 in the present setting.

First, the Senate Report emphasizes that Section 504 "constitutes the establishment of a *broad government policy* that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap" (S. Rep. 93-1297, *supra*, at 39 (emphasis added)). Second, and in a related vein, the report states that "Section 504 was enacted to prevent discrimination against *all* handicapped individuals * * * in relation to Federal assistance in employment, housing, transportation, education, *health services*, or any other Federally-aided programs." *Id.* at 38 (emphasis added). The exception the court of appeals carved out of Section 504 for medical treatment decisions affecting handicapped infants is inconsistent with these statements of congressional intent to take an all-inclusive approach.[24]

Third, the Senate Report reiterates that Section 504 "was patterned after" Title VI of the Civil Rights Act of 1964 (S. Rep. 93-1297, *supra*, at 39) and that discrimination on the basis of handicap "is similar to discrimination because of race" (*id.* at 38). As Judge Winter explained in his dissenting opinion in *University Hospital*, Congress thereby determined that, "so far as the administration of federal financial assistance is concerned, discrimination on the basis of a hand-

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[23] Rehabilitation Act Amendments of 1974, § 111(a), Pub. L. No. 93-516, 88 Stat. 1619, codified at 29 U.S.C. 706(7)(B).

[24] This Court consistently has relied on the Senate Report on the 1974 Amendments as an authoritative exposition of the congressional intent underlying Section 504. See *Davis*, 442 U.S. at 406 n.6; *Gottfried*, 459 U.S. at 509; *Darrone*, slip op. 10 n. 15; *Alexander* v. *Choate*, slip op. 5 n.7, 16 n.24, 18-19 & n.27. There was no House Report on the bill. An identical bill (H.R. 14225, 93d Cong., 2d Sess.) previously had passed the House and Senate and had been subjected to a pocket veto by the President on October 29, 1974. See S. Rep. 93-1297, *supra*, at 1-2. The Conference Report on that earlier bill contains a discussion of the amendments to the term "handicapped individual" (see S. Conf. Rep. 93-1270, 93d Cong., 2d Sess. 25-28 (1974)) that is virtually identical to that in S. Rep. 93-1297, and the discussion in the latter report therefore can be viewed as expressing the view of both Houses.

icap should be on statutory par with discrimination on the basis of race" (Pet. App. 43a-44a).[25] Accordingly, as Judge Winter concluded, just as "[a] judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment" and is prohibited by Title VI, "[s]o, too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment" and is prohibited by Section 504 (Pet. App. 44a). See also 48 Fed. Reg. 30847 (1983).

Finally, the Senate Report makes clear that although Section 504 as originally enacted did not specifically require the issuance of regulations or provide for enforcement procedures, "it is clearly mandatory in form, and such regulations and enforcement are intended" (S. Rep. 93-1297, *supra*, at 39-40). The Report states in this regard that HEW had "experience in dealing with handicapped persons and with the elimination of discrimination in other areas," and that HEW therefore should assume the lead role in implementing Section 504 (*id.* at 40). Congress's acknowledgment of HEW's expertise and its intent that HEW promulgate regulations to effectuate the broad policy of Section 504 require that particular deference be given to the product of the Secretary's deliberations. *Alexander* v. *Choate*, slip op. 16 & n.24; *Darrone*, slip op. 10 & n.15.[26]

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[25] In *Alexander* v. *Choate*, the Court observed that "too facile an assimilation of Title VI law to § 504 must be resisted" (slip op. 5 n.7). But that observation was made in connection with the question whether Section 504 itself forbids conduct that has the *effect* of discriminating, even though Title VI itself does not. See *Guardians Association* v. *Civil Service Commission*, 463 U.S. 582 (1983). The regulations and guidelines at issue in this case, by contrast, address instances of *intentional* discrimination: the withholding of medical treatment from an infant "because of," not "in spite of" or without regard to, his handicap. *Personnel Administrator* v. *Feeney*, 442 U.S. 256, 279 (1979).

[26] Another aspect of the 1974 Amendments also supports the Secretary's interpretation. Title III of those Amendments, 88 Stat. 1631 *et seq.*, provided for the President to call a White House Conference on Handicapped Individuals. Congress directed the Conference to consider, inter alia, ways of "provid[ing] * * * health and diagnostic services for all children early in life so that handicapping conditions may be discovered and treated."

b. An additional backdrop for the 1974 amendments further supports the Secretary's interpretation of Section 504, for in that same year Congress reenacted and expanded the coverage of another statute that specifically prohibits discrimination in admissions and treatment by federally assisted hospitals. As we explain below (see pages 41-43, *infra*), this provision has a direct nexus to Section 504.

The statutory provision involved had been enacted in 1970,[27] and it stated in relevant part (42 U.S.C. (1970 ed.) 4581(a)):

> Alcohol abusers an[d] alcoholics shall be admitted to and treated in private and public general hospitals, which receive Federal funds for alcoholic treatment programs, on the basis of medical need and shall not be discriminated against solely because of their alcoholism.

This statute directly parallels the Secretary's interpretation of Section 504, which likewise requires that treatment decisions be made on the basis of medical need and that the protected individuals not be discriminated against solely because of their handicap.[28] Thus, even prior to the enactment of Sec-

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§ 302(d)(1), 88 Stat. 1632. The Senate Report explains Congress's concern in terms that bear on this case (S. Rep. 93-1297, *supra*, at 50):

> It is against the basic tenets of the scientific process to make an assumption of no hope and no help. No less should be true of public policy. In the case of individuals with handicaps, making this assumption all too often has resulted in the violation of their basic rights as human beings, and has condemned them to live useless lives. Foresight and a strong commitment to the worth and dignity of the human life could have allowed them to live their lives with respect and dignity as first class citizens.

The Report also states (*id.* at 56) that the Conference should make recommendations "on how to change programs in health * * * to ensure that individuals with severe and multiple handicaps will have their needs met." Congress's concurrent efforts to advance health care to benefit handicapped children and to prevent discrimination against handicapped persons converge in the instant case. See *Grove City*, slip op. 7.

[27] Pub. L. No. 91-616, § 321(a), 84 Stat. 1852.

[28] An Assistant Secretary of HEW expressed the Department's support for the alcoholism provision in terms that apply equally to Section 504:

> *Federal policy which prohibits discrimination on the basis of diagnosis is valid and justifiable.* It is our opinion that alcoholics should be admitted to medical care facilities on an equal basis as persons who suffer other illnesses and that alcoholics should not be refused admission on the basis of their alcoholism. We fully agree that hospitals should admit and treat alcoholics on the basis of medical needs.

tion 504 in 1973, Congress had prohibited federally funded hospitals from discriminating on the basis of one type of handicap—alcoholism (see pages 41, 42-43, *infra*)—in the furnishing of medical treatment.[29]

In 1974, Congress reworded and expanded this provision to prohibit discrimination on the basis of alcoholism by all hospitals that receive *any* form of federal financial assistance, not only funds for alcohol treatment programs.[30] Respondent American Hospital Association (AHA) opposed this provision in terms that are essentially identical to respondents' submission in this case. Thus, the AHA expressed the view that "the admission of patients to a hospital and the treatment of patients in a hospital are matters for professional decision on the basis of medical need" and that "priority for admission of patients to a hospital should not be dictated by laws but by the medical needs of the patients."[31] Congress,

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Alcoholic Abuse and Alcoholism Prevention, Treatment, and Rehabilitation: Hearings on S. 3835 Before the Special Subcomm. on Alcoholism and Narcotics of the Senate Comm. on Labor and Public Welfare, 91st Cong., 2d Sess. 146 (1970) (emphasis added). See also *id.* at 65, 76-77, 90, 104-105, 114, 175; H.R. Rep. 91-1663, 91st Cong., 2d Sess. 12 (1970).

[29] In 1972, Congress enacted a similar statute providing that drug abusers who are suffering from "emergency medical conditions" "shall not be refused admission or treatment, solely because of their drug abuse or drug dependence," by any federally assisted general hospital. Pub. L. No. 92-255, § 407, 86 Stat. 78. In 1976, Congress amended this statute to delete the requirement that the drug abuser have an "emergency" condition and to provide that such persons may not be "discriminated against in admission or treatment," rather than "refused" admission or treatment. Pub. L. No. 94-237, § 6(a), 90 Stat. 244. This provision is now codified at 42 U.S.C. (Supp. I) 290ee-2.

[30] Pub. L. No. 93-282, § 121(a), 88 Stat. 130. As amended in 1974, the section provided (42 U.S.C. (1970 ed. Supp. IV 1974) 4581(a)):

> Alcohol abusers and alcoholics who are suffering from medical conditions shall not be discriminated against in admission or treatment, solely because of their alcohol abuse or alcoholism, by any private or public general hospital which receives support in any form from any program supported in whole or in part by funds appropriated to any Federal department or agency.

This provision was further amended in 1976 to apply to federally assisted outpatient facilities as well. Pub. L. No. 94-371, § 11(a), 90 Stat. 1041. As so amended, the provision is now codified at 42 U.S.C. (Supp. I) 290dd-2(a).

[31] See *Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act Amendments, 1973: Hearings on S. 1125*

however, rejected the AHA's position that federal law has no role in preventing discrimination in the furnishing of medical treatment. The Senate Committee noted that the AHA's own policy statement, adopted in 1969, took the position that "[f]ailure to admit alcoholics and patients with other drug problems denies them the benefits that would be available in cases of poisoning due to other causes" and that "[d]ecisions concerning admission of these persons should be based only on the needs of the individual." S. Rep. 93-208, 93d Cong., 1st Sess. 14 (1973). The Committee further explained that, contrary to the AHA's view, the statutory provision "does not dictate the admission of patients to hospitals. It provides that alcoholics not be discriminated against in admission or treatment policies of the general hospitals." *Id.* at 14.[32] This is the same principle that the Secretary has applied in interpreting Section 504 as applied to a hospital's discrimination against handicapped infants on the basis of their handicaps.

4. HEW's Promulgation of the Section 504 Regulations in 1977

a. Consistent with Congress's intent, HEW published regulations to implement Section 504 on May 4, 1977. See 42 Fed. Reg. 22677. Those regulations contain a subpart that specifically applies to federally assisted health services programs, along with social service and welfare programs. See 45 C.F.R. Pt. 84, Subpt. F. They state, inter alia, that in providing health "services or benefits" under such a program, the recipient may not, solely on the basis of handicap, "[d]eny a qualified handicapped person these benefits or services," or "[a]fford a qualified handicapped person an opportunity to

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Before the Subcomm. on Alcoholism and Narcotics of the Senate Comm. on Labor and Public Welfare, 93d Cong., 1st Sess. 303 (1973). The AHA unsuccessfully opposed the nondiscrimination provision on similar grounds in 1970. See *1970 Hearings*, *supra* note 28, at 176.

[32] The Senate Report quoted in the text was prepared by the Senate Committee on Labor and Public Welfare, the same Committee that had jurisdiction over the Rehabilitation Act of 1973, and the Report was issued on June 13, 1973, only one month before that Committee issued its report on the Senate version of the bill that became the Rehabilitation Act of 1973. See S. Rep. 93-318, 93d Cong., 1st Sess. (1973).

receive benefits or services that is not equal to that offered nonhandicapped persons." 45 C.F.R. 84.52(a)(1)-(2). However, the regulations, like Section 504 itself, do not require that the benefits or services afforded handicapped persons produce the identical result or level of achievement as they do for a nonhandicapped person. 45 C.F.R. 84.4(b)(2). See *Alexander* v. *Choate*, slip op. 16. They require only "evenhanded treatment." *Ibid.*; *Davis*, 442 U.S. at 410. With regard to medical treatment decisions, an explanatory note states (45 C.F.R. Pt. 84, App. A para. 36 (emphasis added)):

> [A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. *It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.*

These provisions of the 1977 regulations thus make clear that Section 504 prohibits the denial of medically needed treatment based solely on the individual's handicap. There is no basis for excluding handicapped infants from their coverage.[33]

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[33] The court of appeals erred in stating that the Secretary had disclaimed any authority with respect to decisions concerning medically indicated treatment of handicapped infants when the present Section 504 regulations were proposed in 1976, and in discounting the Secretary's interpretation on that ground (see Pet. App. 18a-19a, 25a). All that the Secretary determined in 1976 was that Section 504 did not authorize regulations "concerning adequate and appropriate psychiatric care or safe and humane living conditions for persons institutionalized because of handicap or concerning payment of fair compensation to patients who perform work." 41 Fed. Reg. 29548, 29559 (1976). In other words, Section 504 was not understood to confer on institutionalized persons a per se right to safe conditions or to treatment. Compare *Youngberg* v. *Romeo*, 457 U.S. 307 (1982). This conclusion of course was consistent with the fact that, as relevant here, Section 504 is essentially concerned only with discrimination in the *relative* treatment of handicapped and nonhandicapped persons and does not confer any *absolute* right to receive particular services or benefits under federally assisted programs. Moreover, when the Secretary promulgated the instant regulations in 1984, she distinguished the Department's comments during the rulemaking proceedings in 1976 on the ground that they addressed this distinct question of an institutionalized person's right to treatment. 49 Fed. Reg. 1636 (J.A. 60). The Department's interpretation of its own prior regulatory action is entitled to particular deference. *Udall* v. *Tallman*, 380 U.S. 1, 16-17 (1965).

b. The regulations promulgated by the Secretary in 1977 also specifically address the subject of furnishing medical treatment to alcoholics and drug addicts in a way that bears on this case. First, on a question that had generated much controversy, the Secretary concluded that alcoholism and drug addiction are "physical or mental impairments" within the meaning of 29 U.S.C. 706(7) and that alcoholics and drug addicts therefore are "handicapped individuals" within the meaning of Section 504 if their impairments substantially limit their major life activities. 45 C.F.R. Pt. 84, App. A para. 4. The Secretary expressly concurred in the opinion of the Attorney General on this question (*ibid.*), which stated (43 Op. Att'y Gen. No. 12 (Apr. 12, 1977), at 10 (emphasis added)):

> The congressional purpose expressed in [S. Rep. 93-1297, *supra*, at 38] to prevent discrimination on the basis of an essentially irrelevant criterion would appear to apply where the handicap involved is alcoholism or drug addiction as it does to other diseases. For example, *Congress could reasonably have concluded that an alcoholic or drug addict not be denied treatment in a federally-assisted hospital for a serious injury solely because he was an alcoholic or drug addict, as long as he "otherwise qualified" for such treatment.*

This formal opinion of the Attorney General thus directly supports the Secretary's interpretation that Section 504 prohibits discrimination on the basis of handicap in the furnishing of health services and the Secretary's understanding of the significance of the term "otherwise qualified" in this setting.

Second, the 1977 regulations specifically provide that a general hospital or outpatient clinic that receives federal financial assistance "may not discriminate in admission or treatment against a drug or alcohol abuser or alcoholic who is suffering from a medical condition, because of the person's drug or alcohol abuse or alcoholism." 45 C.F.R. 84.53. In an explanatory analysis, the Secretary stated that this provision was included pursuant to the special statutory provisions prohibiting discrimination against alcoholics and drug abusers,

discussed above. See pages 37-39 and note 29, *supra*. But the Secretary continued: "Section 504 itself also prohibits such discriminatory treatment and, in addition, prohibits similar discriminatory treatment by other types of health providers." 45 C.F.R. Pt. 84, App. A para. 37. These provisions again confirm that the application of Section 504 to medical treatment decisions was firmly established in the administrative framework when Congress next turned its attention to Section 504.

5. The 1978 Amendments to the Rehabilitation Act

In 1978, Congress amended the Rehabilitation Act in several respects that again are relevant to the issue in this case. Pub. L. No. 95-602, 92 Stat. 2955 *et seq*. First, Congress added Section 505(a)(2) to the Act (92 Stat. 2983) to provide that the "remedies, procedures, and rights set forth in title VI of the Civil Rights Act of 1964" shall be available to any person aggrieved by a violation of Section 504. 29 U.S.C. 794a(a)(2). The Senate Report stresses the "parallel relationship between section 504 and title VI" (S. Rep. 95-890, 95th Cong., 2d Sess. 19 (1978)), lending further force to the parallel upon which the Secretary relied. The Report also states that HEW's regulations "with respect to procedures, remedies, and rights under Section 504 conform with those promulgated under Title VI. Thus, this amendment codifies existing practice as a specific statutory requirement." *Ibid.* The Court has understood this action by Congress in 1978 to constitute a general endorsement of HEW's Section 504 regulations. *Alexander* v. *Choate*, slip op. 16 n.24; *Darrone*, slip op. 10 & nn. 15, 16.

Moreover, in response to specific concerns in the employment context regarding the interpretation by the Secretary and the Attorney General that the term "handicapped individual" includes alcoholics and drug addicts, Congress amended the definition of that term for purposes of Section 504 to exclude from coverage, in the employment context, any person whose current use of alcohol or drugs prevent him from performing the duties of the job or would constitute a direct threat to property or the safety of others. 29 U.S.C. 706(7)(B). However, Congress at the same time ratified the Secretary's coverage of alcoholics and drug abusers under

other programs. See H.R. Rep. 95-1149, 95th Cong., 2d Sess. 22-23 (1978); H.R. Conf. Rep. 95-1780, 95th Cong., 2d Sess. 102 (1978). The debates establish that Congress was fully aware of the circumstances of the Secretary's interpretation that alcoholics and drug addicts are covered, and portions of the Attorney General's opinion were quoted with approval on that question. 124 Cong. Rec. 30322-30325, 37509-37510 (1978). As we have pointed out (see page 41, *supra*), the Attorney General's opinion had specifically concluded that a federally assisted hospital is prohibited by Section 504 from denying treatment because of a person's handicap—in that case, alcoholism or drug addiction. Moreover, Senator Williams stated that he preferred the Senate bill to the House bill, which would have excluded alcoholics and drug addicts from the protection of Section 504 in "health" and other programs. *Id.* at 30323. And Senator Hathaway observed that the provisions of the comprehensive alcohol and drug abuse statutes already prevented discrimination against alcoholics and drug addicts "in hospital and outpatient services," and he stated that Section 504 also barred such discrimination at federally-assisted hospitals under the Medicare and Medicaid Programs. *Id.* at 30325.

It thus is clear that Congress in 1978 did not view the application of Section 504 to prohibit a federally assisted health care provider from refusing to furnish medical treatment solely because of the patient's handicap as an unwarranted or unprecedented extension of federal authority, as the court of appeals seemed to believe. Rather, Congress, like the Secretary, viewed Section 504 as consistent in this respect with the narrower statutes applicable to alcoholics and drug abusers, which themselves manifested a rejection by Congress of the proposition advanced by respondent AHA that federal law should play no role in assuring nondiscriminatory treatment. Nothing in the 1978 amendments suggests that Congress intended to exclude handicapped infants from this broader protection that Congress affirmed under Section 504. To the contrary, in another provision added by the 1978 Act, Congress once again exhibited a special concern for handicapped children under the Rehabilitation Act by establishing a special program for young children, principally

those up to the age of three, who were "severely handicapped."[34]

6. The Promulgation of the 1984 Regulations and Interpretative Guidelines

In 1984, when the Secretary promulgated the regulations and interpretative guidelines at issue in this case, she made clear that they did not for the first time establish the application of Section 504 to the withholding of medical treatment from handicapped infants. That application, she explained, was already established by Section 504 itself and by the comprehensive implementing regulations promulgated in 1977. 49 Fed. Reg. 1628 (J.A. 34). And, indeed, in May 1980, HHS formally resolved a Section 504 complaint against a hospital arising out of the death of an infant with Down's Syndrome who also had an intestinal blockage.[35] As we have shown, this interpretation of Section 504 is compelled by its plain language and is firmly supported by the circumstances of each stage in its statutory and administrative evolution.

After the regulations and interpretative guidelines were adopted in January 1984, Congress enacted the Child Abuse Amendments of 1984. Those amendments, like the Section 504 regulations, seek to encourage the establishment of Infant Care Review Committees in hospitals by directing the Secretary to develop a model for such a Committee, and they require state child protective services agencies, as a condition to receiving federal funds, to have procedures for receiving and responding to reports of the withholding of medical treatment from handicapped infants. See notes 4 and 5, *supra*. In this way, Congress has built upon and put into

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[34] The new provision, 29 U.S.C. 762(11), authorizes a medical research and demonstration project to develop innovative ways to furnish diagnosis, infant stimulation, therapy, counseling and other services to such children and their parents.

[35] In the compliance agreement, the hospital committed itself to report to the state child protective services agency any cases involving a lack of parental consent to medically indicated treatment for handicapped infants in the same manner as it reported similar cases involving nonhandicapped children. See 48 Fed. Reg. 30847-30848 (1983).

statutory form two important features of the Secretary's administrative efforts under Section 504.

However, the 1984 Amendments, which principally concern the funding of state child protective services agencies, do not impose a direct obligation on the hospitals themselves not to withhold medical treatment from handicapped infants solely because of their handicaps.[36] That is the province of Section 504. The application of Section 504 to the hospitals serves to fill out the shared responsibility of the federal government, the States, and federally assisted hospitals in addressing this problem, which Congress, in enacting the 1984 Amendments, determined to be one of substantial national importance and concern. As the Secretary explained when she promulgated the regulations and interpretative guidelines under Section 504 in 1984, the existence of review mechanisms within the hospitals and state agencies may well make direct federal involvement unneccessary in most cases. But Section 504 affords essential protection as regards the responsibilities of federally assisted hospitals under this arrangement. The Federal Government pays approximately one-third of the total budget of the Nation's hospitals—almost $48 billion in 1982 alone. 49 Fed. Reg. 1639 (J.A. 72). There is nothing unfair or intrusive about a provision of

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[36] The 1984 Amendments did not by statute resolve the question of the application of Section 504 in this setting. Section 127(a) of the Amendments (98 Stat. 1754) states that nothing in them "is intended to affect any right or protection under section 504." Sponsors of compromise language in the substantive provisions of the 1984 Amendments viewed this language in Section 127(a) as embodying a "policy of neutrality" on the question of the application of Section 504. 130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984). Nevertheless, as we have explained more fully in our Reply Brief at the petition stage (at 8-9 & n.4), there were numerous passages in the committee reports and debates on the 1984 Amendments stating that the withholding of medical care from handicapped infants because of their handicap is a form of discrimination, endorsing the application of Section 504 in this setting, and expressing the view that the bill would build upon the Secretary's enforcement efforts under Section 504. See H.R. Rep. 98-159, 98th Cong., 1st Sess. 3 (1983); S. Rep. 98-246, 98th Cong., 1st Sess. 5-11 (1983); 130 Cong. Rec. H379, H380 (daily ed. Feb. 2, 1984) (remarks of Rep. Murphy); *id.* at H381, H382, H384, H385 (remarks of Rep. Erlenborn); *id.* at H388 (remarks of Rep. Biaggi); *id.* at H393 (remarks of Rep. Chandler); *id.* at H395 (remarks of Rep. Hyde); *id.* at H396, H400 (remarks of Rep. Miller); *id.* at H397 (remarks of Rep. Quillen).

federal law that requires the hospital programs receiving these funds to refrain from discriminating on the basis of handicap in furnishing benefits and services.

CONCLUSION

The judgment of the court of appeals should be reversed.

Respectfully submitted.

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APPENDIX

STATUTORY PROVISIONS INVOLVED

1. Section 504 of the Rehabilitation Act of 1973, as codified at 29 U.S.C. 794, provides:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of the title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulation may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

2. Section 7(7)(B) of the Act, 29 U.S.C. 706(7)(B) provides:

> Subject to the second sentence of this subparagraph, the term "handicapped individual" means, for purposes of subchapters IV and V of this chapter, any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment. For proposes of sections 793 and 794 of this title as such sections relate to employment, such term does not include any individual who is an alcoholic or drug abuser whose current use of alcohol or drugs prevents such individual from performing the duties of the job in question or whose employment, by reason of such current alcohol or drug abuse, would constitute a direct threat to property or the safety of others.

3. Section 505(a)(2) of the Act, as codified at 29 U.S.C. 794a(a)(2) (brackets in original), provides:

> The remedies, procedures, and rights set forth in title VI of the Civil Rights Act of 1964 [42 U.S.C. 2000d et seq.] shall be available to any person aggrieved by any act or failure to act by any recipient of Federal assistance or Federal provider of such assistance under section 794 of this title.

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(17)

No. 84-1529

IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, Secretary
of Health and Human Services,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari To The United States Court of Appeals For The Second Circuit

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American Hospital Association, et al.

Nov. 4, 1985

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QUESTION PRESENTED

Whether, in the absence of a clear statement of congressional intent, section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, may be implied to authorize federal intervention in medical treatment decisions made concerning seriously-ill infants.

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

MARGARET M. HECKLER, Secretary
of Health and Human Services,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari To The United States Court of Appeals For The Second Circuit

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BRIEF FOR THE RESPONDENTS AMERICAN HOSPITAL ASSOCIATION, *ET AL.*

This brief is submitted on behalf of the respondents the American Hospital Association ("AHA"), the Hospital Association of New York State ("HANYS") and Strong Memorial Hospital of the University of Rochester.[1]

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[1] AHA has no parent or non-wholly-owned subsidiary companies; its only affiliate is the Hospital Research and Educational Trust. HANYS has no parent or non-wholly-owned subsidiary companies; its only affiliate is the Hospital Educational and Research Foundation. Strong Memorial Hospital, which has no affiliates or subsidiaries, is a division of the University of Rochester, a not-for-profit corporation organized under the laws of New York.

The additional respondents, the American Medical Association, *et al.*, who were plaintiffs in a suit consolidated with that of the AHA, *et al.*, below are filing a separate brief on the merits.

STATEMENT

A. Introduction

This case involves an unprecedented attempt by the federal government, through regulations promulgated under the purported authority of section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794,[2] to intercede in medical decision-making concerning the treatment of newborn infants who are seriously ill. Although the Secretary of the United States Department of Health and Human Services ("DHHS") acted with an understandable motive—to prevent the repetition of a highly publicized case of apparent neglect—she did so through a regulatory effort which, as the United States Court of Appeals for the Second Circuit held, contradicted the specific terms and intent of the Rehabilitation Act. That effort also was unsupported by the clear statement of congressional intent necessary to permit such federal intervention, especially in view of the recent reaffirmation by Congress of the traditional role of the States in the protection of children. Finally, the regulatory imposition upon hospitals was inconsistent with hospitals' role and authority.

B. The Judgment Before This Court

The instant case was initiated on April 6, 1983, when AHA, HANYS and Strong Memorial Hospital filed their initial complaint in the Southern District of New York seeking an injunction against an interim final regulation promulgated by DHHS under authority alleged pursuant to section 504. *American Hospital Association, et al.* v. *Heckler*, 83 Civ. 2638-CLB (S.D.N.Y.). The regulation subjected hospitals to unprecedented and disruptive investigative activity through which petitioner sought to alter what the government inaccurately believed to be the course of medi-

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[2] Section 504 provides in material part that:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . .

cal treatment decisions being made concerning seriously-ill infants.

On March 12, 1984, respondents amended their complaint to allege that, in view of the decision of the United States Court of Appeals for the Second Circuit in *United States* v. *University Hospital of the State University of New York at Stony Brook ("University Hospital")*, 729 F.2d 144 (2d Cir. 1984), the district court was required to hold that a subsequent version of the DHHS regulation, 49 Fed. Reg. 1622 (1984), had been adopted without statutory authority and, pursuant to the Administrative Procedure Act, 5 U.S.C. § 706(2)(C), must be set aside.[3]

In *University Hospital*,[4] the court of appeals, rejecting DHHS' attempt to obtain hospital records[5] concerning the treatment of an infant who became known as "Baby Jane Doe," held that section 504 does not "apply to treatment decisions involving defective newborn infants" and that, "[u]ntil Congress has spoken," DHHS could not investigate. 729 F.2d at 161.[6]

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[3] On the same day, the American Medical Association and others filed a companion case, with essentially the same basis as the instant action. The district court ordered the consolidation of the two matters with the consent of the government.

[4] The *University Hospital* decision and the instant case can be viewed together because the Second Circuit, in summarily affirming this case, relied exclusively upon *University Hospital*.

[5] Because the DHHS section 504 interim final regulation directed at medical treatment had been declared invalid in the *American Academy of Pediatrics* v. *Heckler*, 551 F. Supp. 395 (1983), DHHS claimed authority for this activity under its general regulation, promulgated under section 504, governing access to records. 45 C.F.R. § 84.61 (1982), incorporating 45 C.F.R. § 80.6(c). The general regulation does not mention hospitals or medical treatment.

[6] The Second Circuit based its opinion upon its holding that, *inter alia*: (1) seriously-ill newborn infants could not be "otherwise qualified" or "subjected to discrimination" within the meaning of section 504 (729 F.2d at 155-57); (2) the legislative history of the statute shows no congressional intention to involve the federal government in the regulation of medical treatment, an area traditionally dealt with by the States (*id.* at 157-61); and (3) such regulation would impose onerous affirmative action

Shortly after the court of appeals denied a motion for *en banc* rehearing of the *University Hospital* case, the district court in the case at bar issued a Final Judgment, holding that DHHS "has no authority under section 504 to investigate or to otherwise regulate treatment decisions involving impaired newborn infants." *American Hospital Association, et al.* v. *Heckler*, 83 Civ. 2638 (CLB) (S.D.N.Y. June 11, 1984), slip op. at 3.

Consequently, the district court invalidated the final regulation and enjoined DHHS from "continuing or undertaking any other actions to investigate or regulate treatment decisions involving impaired newborn infants taken under authority of section 504 . . . ." *Id.* at 4. This judgment was summarily affirmed by Order of the court of appeals. *American Hospital Association, et al.* v. *Heckler*, No. 84-6211 (2d Cir. December 27, 1984). The petition for a writ of *certiorari* followed.

C. Factual and Legal Background of the Instant Case

1. The genesis of the regulatory effort

Section 504, neither as enacted nor as amended, contains any enforcement directives, investigative procedures or sanctions provisions. However, when it amended the Act in 1974, Congress envisioned that the heads of each federal agency would promulgate comprehensive regulations to implement it. *Cherry* v. *Mathews*, 419 F. Supp. 922, 924 (D.D.C. 1976), and authorities cited therein.[7]

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burdens on hospitals in contravention of *Southeastern Community College* v. *Davis*, 442 U.S. 397, 441 (1979) (*id.* at 160).

[7] From the outset, the Secretary of what is now DHHS recognized that, although section 504 was patterned upon the prohibition against racial discrimination contained in Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d, *et seq.*, important differences between the two statutes required differing approaches to eliminating the types of discrimination prohibited under those two statutes. For example, as to section 504, the Secretary hypothesized: "handicapped persons may require different treatment in order to be afforded equal access to federally assisted programs and activities, and *identical treatment may, in fact, constitute discrimination.*" 41 Fed. Reg. 20296 (1976), emphasis supplied.

When the Department of Health, Education and Welfare (DHHS' predecessor agency) promulgated its draft section 504 regulations in 1976, the Secretary specifically sought public comment on "[w]hether a regulation should contain provisions concerning patients' rights to receive or refuse treatment." 41 Fed. Reg. 20297 (1976). Thereafter, when the Agency published a proposed rule, which became effective in 1977, the Secretary concluded that the Act provided no authority for a rule which applied to an "institutionalized person's right to receive or refuse treatment." 41 Fed. Reg. 29559 (July 16, 1976).

Notwithstanding this thoughtful and unequivocal pronouncement, an unfortunate event occurred five years later that led the Secretary abruptly to jettison this position. In early April of 1982, a baby with Down syndrome and an esophageal obstruction that prevented normal feeding was born in Bloomington, Indiana. The obstruction was reported to be surgically correctable, but the infant's parents refused to consent to treatment. Thereupon, the hospital initiated state court proceedings which led to the appointment of a guardian *ad litem* and the undertaking of appeals. The courts refused to intervene, however, and the infant died. *See American Academy of Pediatrics* v. *Heckler,* 551 F. Supp. 395, 397 (D.D.C. 1983).

The death of the Bloomington "Baby Doe" was widely publicized and resulted in a considerable amount of critical public comment. Citing this incident, President Reagan sent a memorandum dated April 20, 1982, to the Attorney General and to the Secretary of DHHS noting that discrimination against the handicapped in programs or activities receiving federal financial assistance is prohibited by section 504. *See* 48 Fed. Reg. 9630 (1983). DHHS responded to the President's memorandum on May 18, 1982, by issuing a "Notice to Health Care Providers" published in 47 Fed. Reg. 26027 (June 16, 1982), J.A. 127-128.[8]

In that Notice, the Secretary undertook to reverse the Department's long-held position on section 504 and in-

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[8] *See* n. 27 *infra.*

formed affected parties that medical-treatment decisions involving newborn infants with birth defects were deemed to be within the reach of federal intervention under section 504. The Notice concluded that "[t]he failure . . . to comply with the requirements of section 504 subjects that recipient to a possible termination of Federal assistance." *Id.* No further sanctions or federal enforcement activities were prescribed in that Notice.

Almost a year later, on March 7, 1983, without any notice of proposed rulemaking or opportunity for comment, a new Secretary of DHHS promulgated an interim final rule directed not at "affected parties," but solely at *hospitals.* The rule expanded upon the earlier Notice by adding sanctions and intrusions and a requirement for hospitals to display posters in conspicuous places in every delivery, maternity and pediatric ward and in each nursery declaring,

> DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW.
>
> Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: Handicapped Infant Hotline.

The "Handicapped Infant Hotline" would be available 24-hours-a-day to all persons who wished to make complaints, including anonymous complaints. Moreover, in the preamble to the rule, DHHS asserted authority to conduct immediate investigations and make immediate referrals to the Department of Justice for such legal action as might be found necessary. 48 Fed. Reg. 9630, 9631, effective March 22, 1983.

2. The effect of the rule in hospitals

Although medical treatment decisions regarding infants are made by parents who are advised by physicians,[9] the interim final rule and its successors are directed at hospitals, which are alleged to be the recipients of federal financial assistance through Medicare payments. This focus has

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[9] See pp. 26-28 *infra.*

created severe problems in hospitals through its fundamental and essential distortion of the respective roles and responsibilities of parents, physicians and hospitals.

From the outset, enforcement of the rule adversely affected hospitals' operations and jeopardized the provision of health care services to the very infants the rule allegedly was designed to protect. At Strong Memorial Hospital, for example, DHHS Office of Civil Rights ("OCR") investigators, during March 29-30, 1983, conducted an investigation pursuant to an anonymous hotline tip reporting that conjoined (siamese) twins under the Hospital's care might be denied nutrition or treatment. *See* Affidavit of Paul M. Rosenberg, J.A. 178-182.[10] On March 29, 1983, after reviewing the patients' medical records, lay investigators employed by DHHS engaged the patients' attending physician in a disconcerting and lengthy interview about the patients' conditions and the nature of the medical decision-making regarding them. J.A. 179.

Subsequently, a physician/investigator insisted upon examining the infants and reviewing their medical records. J.A. 180. Both the children's parents and the hospital on their behalf refused to authorize such examination and review, and the investigative squad ultimately departed. J.A. 180-181.

The investigation itself, as well as the numerous newspaper accounts which appeared in the Rochester region, generated fears in the patients' family that any further decisions that it made would have been subject to similar scrutiny. J.A. 181. As a result, the Hospital's ability to assist the family and physicians in formulating an appropriate care plan for these infants was compromised. *Id.*

The effect of the investigation, however, was broader. The parents of other critically-ill children began to question whether their children were being harmed, and one family even withdrew a seriously-ill patient from Strong Memorial before completion of treatment because of fears

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[10] Petitioner offered no contradiction of the affidavits submitted to the District Court.

engendered by local newspaper accounts of the investigation. *Id.*

The disruptive consequences of this investigation were subsequently summarized in a thoughtful article written by persons directly involved, as follows:

> The family, the primary physician, specialists, and staff of the Neonatal Intensive Care Unit all felt "demeaned" and "under suspicion" as persons and professionals by their awareness of the federal regulations and the presence of investigators.
>
> The normal parental grieving process was altered. During the infants' illness and after their death, the parents frequently expressed confusion, depression, and a sense of disruption of their own lives that went beyond the normal grieving process. This was attributed to the existence of the federal regulations and the investigative process that occurred regarding their infants.
>
> The federal investigation was a public process that drew attention to an ordinarily private situation. Media reports sensationalized the case. The family's privacy was violated by attempts of the media to obtain information. Alterations in hospital security procedure were required to safeguard confidentiality.
>
> The emotional status of other families with infants in the Neonatal Intensive Care Unit was disrupted by the occurrence of a federal investigation into the adequacy of care provided in the Neonatal Intensive Care Unit.
>
> The time of administrators, physicians, family members, and legal counsel was utilized. The presence of a federal investigation necessitated multiple discussions and conferences involving administrative personnel and other consulting persons. A great deal of time and effort on the part of professionals was necessary to resolve the issues.
>
> Many of the above occurrences contributed to an increased cost of care for the infants.

Shapiro and Rosenberg, *The Effect of Federal Regulations Regarding Handicapped Newborns,* 252 J.A.M.A. 2031, 2033 (1984).

A DHHS investigation at Vanderbilt Memorial Hospital on March 23-24, 1983 caused similar disruptions. *See* Affidavit of Norman B. Urmy, J.A. 183-186. That investigation, which was initiated by an anonymous hotline report that alleged that ten named children were not receiving proper treatment or nourishment, resulted in the visit of three Office of Civil Rights non-physician investigators and a physician/consultant. J.A. 183-184.

Based upon their own review of the infants' files, on the afternoon of March 23, 1983, Hospital personnel had concluded that there was no medical basis for the call, since all ten patients were receiving appropriate medical care and nourishment. J.A. 184. That evening, however, Hospital personnel, including the Chief of Pediatrics and the Chief Pediatric Resident, were compelled to meet with the OCR investigators, utilizing medical records to discuss the medical history, course of treatment, nourishment and prognosis of each of the ten children. *Id.* Thereafter, in the company of the Chief of Pediatrics and the Chief Pediatric Resident, the physician/investigator made "rounds" to visit each of the patients. *Id.*

The investigation continued for most of the following day and involved both reviews of records and interviews of administrative, nursing and physician staff. J.A. 184-185. The investigation of this meritless complaint was time consuming, disruptive and expensive. The Chief of Pediatrics worked eight hours with the OCR team, the Associate Director of Nursing worked eighteen hours assisting them, and the Chief Pediatric Resident spent ten hours doing so. Six nurses were interviewed by the OCR team for a total of three hours. These doctors and nurses would, of course, have otherwise spent their time caring for patients. *Id.*

The OCR investigation also had adverse effects on medical care given the ten patients involved. For example, one patient remained in the Pediatric Intensive Care Unit longer than necessary because his chart was unavailable for the house staff to review and write discharge orders.

Additionally, on March 24, the house staff was unable to review laboratory reports and update orders following rounds because the necessary charts were in the possession of the OCR team. Copies of laboratory reports had to be ordered and numerous calls to the laboratory were required to obtain information. J.A. 185. This posed a serious threat to the appropriate care of these infants.

Furthermore, because charts had to be retrieved from the investigators, there were delays in the transporting of patients from the Pediatric Intensive Care Unit to the Operating Room. And finally, six nurses were pulled from patient assignments for interviews with the OCR team several of which occurred during changes of shifts, delaying necessary reports on patients to the nurses on the next shift. J.A. 185-86.

In view of the fact that DHHS's regulatory efforts were triggered by the Bloomington case, it is noteworthy that they uncovered no violation. Indeed, during the period that the regulatory process was in place DHHS received hundreds of hot-line calls and initiated 49 investigations. Yet no call or investigation identified a single case of improper treatment of newborns.

3. Initial litigation and petitioner's response

At a hearing on April 6, 1983, concerning the original complaint in this action filed by AHA, HANYS and Strong Memorial Hospital, based upon the adverse effect the rule was having upon hospitals, the district court issued a temporary restraining order prohibiting defendant "from enforcing [the interim final rule] solely to the extent that it purports to require the posting of notices upon the premises of voluntary or municipal hospitals within New York State . . . ." *AHA* v. *Heckler*, 83 Civ. 2638-CLB (Apr. 6, 1983).

Shortly thereafter, on April 14, 1983, the United States District Court for the District of Columbia ruled that the "interim final rule . . . is invalid as an arbitrary and capricious agency action which fails to meet the standard required under the Administrative Procedure Act, 5 U.S.C.

§ 706(2)(A)." *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 399 (D.D.C. 1983). Although the court in *American Academy* did not determine whether section 504 provided a statutory basis for the interim final rule, it indicated concern about the propriety of extending section 504's reach "into such a sensitive area" without "evidence of [congressional] intent," and expressed the hope "that this will be clarified by further congressional action." *Id.* at 401-402.

Responding to this judicial invalidation, DHHS on July 5, 1983, attempted to comply with Administrative Procedure Act requirements and proposed a somewhat revised rule (48 Fed. Reg. 30846 (1983)), which itself was slightly modified when the Agency issued its final regulation on January 12, 1984. 49 Fed. Reg. 1622 (1984), J.A. 11-126. The essential provisions, including the notices, hotline and investigations, remained. It was this final regulation that was invalidated in the instant case. Section 504 of the Rehabilitation Act was the only authority asserted by DHHS for all of the foregoing regulatory activity.

D. The Child Abuse Amendments of 1984

In February 1984, Congress began its own consideration of the appropriate method of assuring the protection of seriously-ill infants. In September 1984, seven months after the appellate court's decision in *University Hospital* and three months after the district court in the instant case enjoined DHHS from enforcing or implementing its section 504 regulations, or undertaking any related regulatory or investigative activity, Congress enacted the Child Abuse Amendments of 1984, Pub. L. 98-457, 98 Stat. 1749, *et seq.* (1984). This legislation, which amended the Child Abuse Prevention and Treatment Act (42 U.S.C. §§ 5101, *et seq.*), specifically addresses the issue of withholding medically-indicated treatment (including appropriate nutrition) from disabled infants with life-threatening conditions. Significantly, those amendments are altogether consistent with the longstanding primary role of the States in the area of child protection.

The Child Abuse Amendments, which Congress enacted after consultation with a variety of individuals and organizations, including the American Hospital Association, condition the States' continued qualification for certain federal grants upon the States' development and implementation of certain new procedures or programs within their child protective services systems. States must have programs or procedures for the purpose of responding to reports of medical neglect, including withholding of medically-indicated treatment from disabled infants with life-threatening conditions.[11]

The Child Abuse Amendments also require DHHS to promulgate regulations implementing the requirements of the provision described above [42 U.S.C. § 5103(b)(2)(K) (as added by Section 122(3) of Pub. L. No. 98-457)].[12] In addition, the statute requires DHHS to promulgate model guidelines to encourage hospitals to establish committees which would serve the purposes of "educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment from such infants, and offering counsel and

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[11] These programs and/or procedures must provide for:

> (i) coordination and consultation with individuals designated by and within appropriate health-care facilities;
>
> (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions); and
>
> (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Pub. L. No. 98-457, § 122(3), 98 Stat. 1752-53, *amending* 42 U.S.C. § 5103(b)(2).

[12] On April 15, 1985, DHHS published its final rule implementing the Child Abuse Amendments. 45 C.F.R. Part 1340, as amended by 50 Fed. Reg. 14887-92.

review in cases involving disabled infants with life-threatening conditions." Pub. L. No. 98-457, § 124(b)(1), 98 Stat. 1754.

In addition, the Child Abuse Amendments provide a detailed definition of the term "withholding of medically indicated treatment." *See id.*, § 121(3), *amending* 42 U.S.C. § 5102. Significantly, by the terms of that definition there can be *no* impermissible "withholding of medically indicated treatment" when:

> in the treating physician's or (physicians') reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id.

In summary, the Child Abuse Amendments address the issue of medical treatment decisions concerning seriously-ill infants in a detailed and comprehensive manner which recognizes: (a) the States' traditional oversight and enforcement role; (b) the considerable importance of the treating physicians' judgments; and (c) the *inappropriateness* of requiring the provision of treatment in certain statutorily-specified circumstances. *See id.*, §§ 121(3), 122(3).

SUMMARY OF ARGUMENT

The publicity generated by the Bloomington "Baby Doe" case led the federal government to the unsubstantiated belief that a national problem existed that called for direct federal intervention. In the absence of any clear statutory basis for such intervention, petitioner abandoned a clearly-held agency position to the contrary, and took a Procrustean view of section 504 of the Rehabilitation Act of 1973, asserting that it permitted the government to intercede in the medical treatment of seriously-ill infants. This

view is unsupported by any manifestation of congressional intent and otherwise conflicts with law, with the traditions of American medical practice, particularly the attending physicians' professional commitment and devotion to their special mission, and with our culture's emphasis upon parental responsibility and caring.

The plain meaning of section 504 does not support its application to the treatment of seriously-ill infants. As the Court of Appeals held, such infants are not "otherwise qualified handicapped individuals" within the meaning of the statute because the term has no logical application to infants in the context of treatment. Instead, the term "qualified" can only relate to qualification for vocational training and independent-living programs, which require independently demonstrable abilities that would allow successful participation.

There is no meaningful, specific connection between the treatment of infants in hospitals and the statutorily-required "program or activity receiving Federal financial assistance." Medicare and Medicaid are the asserted links, but those programs provide aid to individuals, not to treatment facilities or their activities. Moreover, under the Medicare and Medicaid statutes and the terms and conditions of their acceptance, and the controlling law of this Court, the government may not involve itself in treatment decisions through these programs.

Additionally, and specifically in regard to hospitals, there is no pertinent service from which infants could be shown to be excluded by virtue of unlawful discrimination. A medical treatment decision may be assessed to have been well-founded or inappropriate, but in making such a determination, the impaired child by definition cannot be compared to one who is unafflicted because the medical treatment decisions are necessarily different. Medical decisions are made across a broad continuum of cases of varying complexity and severity, but all of which are united by the fact that there is a patient with an illness or condition as to which treatment is to be considered and choices made.

These choices do not exclude or deny benefits of any program, or discriminate against the impaired individual. Indeed, the choices are compelled precisely because of the existence of the impairment.

If section 504 is at all applicable to hospitals in these circumstances, it is to ensure infants' access to medical services, not to regulate choice of treatment within facilities. However, even petitioner has never suggested that the question of access is at issue, and the regulation that was invalidated below was not directed at guaranteeing access to medical facilities. Instead, its intent was to influence treatment decisions in cases of children who have been afforded access to hospitals. Those treatment choices are not within the compass of the "discrimination" prohibited by section 504.

Should the Court conclude, however, that the language of section 504 is ambiguous on its face or in the application sought, the legislative history of the statute demonstrates the lack of congressional intent to authorize federal intervention in individual medical treatment choices. Petitioner's incomplete or selective quotation of various legislators' pronouncements is at odds with the intention of Congress to guarantee the handicapped access to various programs and facilities, particularly involving education, vocational rehabilitation and living in non-institutional settings.

Finally, with no clear statement of legislative intent to the contrary, Congress cannot be presumed to have superseded the traditional role of the States in dealing with child protection and medical treatment. Indeed, that role was recently reaffirmed in the Child Abuse Amendments of 1984, which serve as part of comprehensive child-protective mechanisms which are in fact assuring that appropriate medical attention is being furnished to seriously-ill infants, without jeopardizing the important and delicate parent-physician relationship in which treatment decisions are considered and made.

ARGUMENT

I. Congress Did Not Intend That Section 504 Of The Rehabilitation Act Of 1973 Would Authorize The Federal Government To Intervene In Medical Treatment Decision-making Concerning Seriously-ill Newborn Infants.

Petitioner's attempts to intervene in the medical treatment of seriously-ill infants through regulations aimed at hospitals came as a result of a Presidential directive occasioned by the death of the Bloomington "Baby Doe" and the widespread publicity and controversy surrounding it. *See* 48 Fed. Reg. 9630 (1983); *American Academy of Pediatrics* v. *Heckler, supra,* 551 F. Supp. at 397; Kuzma, *The Legislative Response to Infant Doe,* 59 Ind. L. J. 377, 377-78, 386 (1984).

There was, in the executive branch of the federal government, the expressed desire to act quickly to prevent the repetition of such a case. However, lacking a federal statute that authorizes DHHS to intervene in medical treatment decisionmaking,[13] petitioner was compelled to contrive some authority to involve the federal government, and so turned to the antidiscrimination provisions of section 504. However, Congress never intended for that statute to apply to the medical treatment of infants or the regulation of such treatment through hospitals.

Congressional intention may be fathomed in two ways: by the plain meaning of the words Congress employed in its enactment; and by an analysis of the legislative history. If the primary inquiry is not determinative because of statutory ambiguity, the Court will turn to the secondary process. Respondents will discuss each in turn.

A. The Plain Meaning of Section 504 Does Not Provide Authority for Petitioner's Attempts To Regulate Hospitals Through Intervention in the Medical Treatment of Seriously-Ill Infants.

This Court has long held that under the "plain meaning rule," the interpretation of a statute "must, in the first in-

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[13] Indeed, there are several which prohibit it. See pp. 23-24, *infra.*

stance, be sought in the language in which the act is framed, and if that is plain, . . . the sole function of the courts is to enforce it according to its terms." *Caminetti* v. *United States*, 242 U.S. 470, 485 (1917). *See American Tobacco Co.* v. *Patterson*, 456 U.S. 63 (1982); *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979). And in analyzing the scope of section 504 itself, this Court only recently held that interpretations stretching the statute beyond "manageable bounds" should be avoided. *Alexander* v. *Choate*, —— U.S. ——, 105 S. Ct. 712, 720 (1985). The protections of section 504 extend only to *"otherwise qualified handicapped individuals,"* to the extent that such a person is within *"any program or activity receiving Federal financial assistance."* If those definitional prerequisites are met, the protected individual may not "be *excluded* from participation . . . be *denied* the benefits of . . . *or* be *subjected to discrimination*" by the federal recipient. In the instant case, petitioner would strain section 504 beyond permissible limits as to the application of each of its operative terms.

1. Infants with birth defects are not "otherwise qualified handicapped individuals" within the means of the statute.

The definition of a "handicapped individual" held by the Court of Appeals to be applicable to hospitalized infants is that contained in 29 U.S.C. § 706(7)(B), which protects "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." *United States* v. *University Hospital, supra*, 729 F.2d at 155.[14]

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[14] This section (7)(B) definition applies for "purposes of subchapters IV and V of this chapter." Subchapter IV, 29 U.S.C. §§ 780-785, concerns the activities of the National Council of the Handicapped, while Subchapter V, 29 U.S.C. §§ 790-794, encompasses "Miscellaneous Provisions" dealing essentially with issues of employment by governmental entities and under federal contracts and the elimination of architectural, transportation and communications barriers.

Although it is readily apparent that seriously-ill infants have significant "physical or mental impairments," these impairments are not relevant to "major life activities" within the meaning of the statute.[15] The Rehabilitation Act does not define the latter phrase, but DHHS's regulations do. Under 45 C.F.R. § 84.3(j)(2)(ii), " 'Major life activities' means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." The focus of this definition is clearly upon the ability to benefit from programs of education, employment opportunities, and independent living and does not apply to newborn infants. See 29 U.S.C. § 701.

The condition of these seriously-ill infants at the time that petitioner would intervene in their treatment is inconsistent with the discussion of their physical abilities, particularly those related to education, training and independent living. This inconsistency becomes even more pronounced when the term "handicapped individual" is read along with the term "otherwise qualified" that precedes it in the statute.

As the Second Circuit held in *University Hospital*, "the government's view of 'otherwise qualified' is divorced from the statutory language." 729 F.2d at 156.

> In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents. If congress intended section 504 to apply in this manner, it chose strange language indeed.

Id. Petitioner's response in this Court is nothing more than an attempt to read the term "otherwise qualified" out of

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[15] The Court of Appeals understood this argument, but noted that the present condition of an infant would affect his or her ability to perform such functions in the future. Therefore, in view of amendments (29 U.S.C. § 762(b)(11)) by which Congress sought to make available rehabilitative services to children of preschool age, the court concluded that a seriously-ill infant is a "handicapped individual" within the definition of section 706(7)(B). Respondents take issue with this conclusion.

the statute in order to apply the statute to medical treatment. In its stead, petitioner would substitute a medical-benefit criterion which is utterly at odds with the statute and those cases interpreting it.

In *Southeastern Community College* v. *Davis, supra,* 442 U.S. at 406, this Court held that an "otherwise qualified handicapped individual" is, within the plain meaning of section 504, "one who is able to meet all of a program's requirements in spite of his handicap." *See Alexander* v. *Choate, supra; Doe* v. *New York University,* 666 F.2d 761 (2d Cir. 1981). In those terms, a handicapped person is protected by that statute, *i.e.,* he or she is "otherwise qualified," when the handicap is an irrelevancy to the acceptable performance of the function encompassed in the covered "program or activity." In other words, a protected handicapped person and a non-handicapped person each have essentially the same basic capabilities necessary for achievement in the same undertaking.[18]

In this analytical mode, the determination of qualification under section 504 of the Rehabilitation Act is essentially the same as the determination of racial discrimination under Title VI of the Civil Rights Act of 1964. In both cases, the distinction is between the function to be performed, for example, work or education, and factors having no bearing on performance, for example, an immaterial physical infirmity or the color of a person's skin. No such separation can be made in the case of the medical treatment of a seriously-ill infant. Here, it is the "handicap," *i.e.,* the illness or birth defect, that is the subject of the medical decision-making process. The term "otherwise qualified" has no meaningful application in this context. *University Hospital, supra,* 729 F.2d at 156.

Petitioner argues that the only legitimate qualification for an infant's medical treatment is the child's admission

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[18] Thus, while a recipient covered by section 504 might be required to make limited reasonable accommodations to handicapped persons, *Alexander* v. *Choate, supra,* section 504 clearly does not impose an "affirmative-action obligation on all recipients of federal funds." *Southeastern Community College* v. *Davis, supra,* 442 U.S. at 411.

to a hospital that is capable of providing services from which he or she might derive some benefit. See Brief for Petitioner at 22-23. This postulation avoids all consequences of the term "otherwise qualified" as it is used in section 504. In the first place, the benefit argument assumes that the covered program or activity is the medical treatment decision itself, an assumption that could never be supported by authority or evidence of congressional intent. In the second place, and more importantly, the infant, under petitioner's argument, is not "one who is able to meet all of a program's requirements *in spite of* his handicap," as the Court required in *Davis*.[17] Instead, the infant is one who requires medical evaluation *because of* his handicap.

In short, petitioner's suggested reading of "otherwise qualified" deprives the term of any meaning consistent with anything that Congress could have contemplated, given the remaining terms of section 504. To apply the term in the context of the medical treatment decision-making process, once an infant has been admitted to a facility where that process can be undertaken. destroys the plain meaning of the term.

2. Given the plain meaning of the statute petitioner can identify no federally-financed program or activity affecting medical treatment decisions from which hospitals could be shown to be discriminating against seriously-ill infants.

"Section 504, by its terms, prohibits discrimination only by a 'program or activity receiving Federal financial assistance.' " *Consolidated Rail Corp.* v. *Darrone*, —— U.S. ——, 104 S. Ct. 1248, 1255 (1984). *See Grove City College* v. *Bell*, —— U.S. ——, 104 S. Ct. 1211 (1984); *North Haven Board of Education* v. *Bell*, 456 U.S. 512 (1982). "Clearly, this language limits the ban on discrimination to the specific program that receives federal funds." *Darrone, supra*, 104 U.S. at 1255. Petitioner only begs the question of whether there is a pertinent program or activity linking hospitals with alleged denials of medical treatment to seriously-ill

[17] 442 U.S. at 406 (emphasis supplied).

infants. A careful analysis shows that there can be no such program or activity applicable in any material way and so, on its face, Section 504 has no applicability to hospitals in the context of medical treatment decisions.

In justifying the regulatory focus on hospitals, petitioner identifies two programs, Medicare and Medicaid (see Brief for Petitioner at 20 n.9), which presumably establish the statutorily-required nexus. However, petitioner readily concedes that because the court of appeals in *University Hospital*, and the district court and court of appeals in the instant case, held in favor of respondents on the supervening question of statutory authority, they "had no occasion to consider whether Medicare or Medicaid payments constitute 'Federal financial assistance' and, if so, what the scope of the assisted 'program or activity' should be." *Id.*[18] For obvious reasons, petitioner would leave that question for another day. *Compare Consolidated Rail Corp.* v. *Darrone*, *supra*. However, the question is susceptible of resolution, and, as a threshold matter, it can be shown that hospitals are not recipients of federal financial assistance having any meaningful connection with the regulatory activity at issue. Moreover, whatever federal financial assistance a hospital might be held to receive has no "program-specific" relationship to medical treatment decision-making, the activity that the government sought to regulate.

a. Medicare and Medicaid do not constitute federal financial assistance.

Respondents submit that Medicare and Medicaid payments do not constitute federal financial assistance to hos-

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[18] Petitioner accurately states that the district court in *University Hospital* held that a hospital's receipt of Medicare and Medicaid payments constituted federal financial assistance, and that holding is consistent with the only court of appeals decision on the subject, *United States* v. *Baylor University Medical Center*, 736 F.2d 1039 (5th Cir. 1984), *cert. denied*, 105 S.Ct. 958 (1985). While respondents submit that these holdings are incorrect, the holdings also cannot determine the question of scope in this case. However, that determination can be made. At its broadest, that scope is insufficient to satisfy facial statutory requirements where a regulation aimed at influencing medical treatment decisions is directed at hospitals.

pitals within the meaning of section 504.[19] The statute does not define the term, and there are very few cases which show a reasoned analysis of the concept.[20] However, Medicare (42 U.S.C. §§ 1395, *et seq.*) and Medicaid (42 U.S.C. § 1396) provide payments ultimately received by hospitals that can hardly be looked at as subsidies to them. Instead, the payments made under both programs are payments for covered services to patients, which payments, by statute, cannot exceed the fair market value of those services.

Under these circumstances, there can be no question that such payments are assistance to the individuals treated, but not to the hospitals where the treatment is provided. *See Cook* v. *Budget Rent-A-Car Corp.*, 502 F. Supp. 494 (S.D. N.Y. 1980). *Cf. Jones* v. *Metropolitan Atlanta Rapid Transit Authority*, 681 F.2d 1376, 1380 (11th Cir. 1982), *cert. denied*, 104 S. Ct. 1591 (1984); *Doe* v. *Region 13 Mental Health-Retardation Commission*, 704 F.2d 1402 (5th Cir. 1983).[21]

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[19] *But see United States* v. *Baylor University Medical Center*, *supra*. Although the government concedes that parents of seriously-ill infants are not recipients of federal financial assistance, and that it cannot regulate parents, 49 Fed. Reg. 1631 (1984) (J.A. 43), nevertheless, DHHS' final rule is—improperly—aimed at regulating or influencing parental decision-making through pressure on hospitals.

[20] The issue did not have to be treated in *Grove City College* v. *Bell*, *supra*, because the Basic Educational Opportunity Grants at issue there were, by the specific terms of the statute authorizing them, federal financial assistance to the college, or as the Court held, to the specific activity—the financial aid office—that processed the funds received from the government. *See* 104 S. Ct. at 1218.

[21] Petitioner essentially argues that if a hospital "sells" its product (*i.e.*, health care services) to beneficiaries of the Medicare or Medicaid programs, the hospital (or, given *Grove City*, *supra*, some part of a hospital) becomes a federally-assisted program. Under the logic of petitioner's argument, any vendor selling goods or services to any federally subsidized entity would thereby become, in some part, a federally-assisted program itself.

However, in its petition for a writ of *certiorari* in *Department of Transportation* v. *Paralyzed Veterans of America*, No. 85-289, seeking reversal of 752 F.2d 694 (D.C. Cir. 1985), *cert. granted*, 54 U.S.L.W. 3262 (U.S.

b. Medicare does not involve the treatment of newborns, and its specific terms prohibit governmental interference in the treatment that it does involve.

Given the fact that the entire purpose of petitioner's invalidated regulation was to affect the care being given to seriously-ill infants, her attempt to satisfy section 504's program-specific requirements by relying upon the Medicare program is a strange anomaly because it does not cover the care of such infants. As 42 U.S.C. § 1395c makes clear, Medicare covers two categories of persons: those over the age of 65; and certain disabled persons under the age of 65 who have been entitled to designated Social Security survivors' benefits for at least 24 months. Those categories do not include the newborn infants with whom the government has been concerned in this case.

As to the care of the aged and disabled which is covered by Medicare, 42 U.S.C. § 1395 provides that:

> Nothing in this title shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided, or over the selection, tenure, or compensation of any officer or employee of any institution, agency, or person providing health services, or to exercise *any super-*

October 22, 1985), the government takes a contradictory view. There, the government criticizes the D.C. Circuit for deciding that the airlines' use of federally-subsidized airports renders the airlines' provision of commercial air transportation a federally-assisted program or activity subject to section 504.

In its petition, the government relied heavily on Judge Bork's dissent from the court's denial of a suggestion for rehearing *en banc* in which he observed that the panel's "reading of section 504's statutory language would make every commercial enterprise a 'recipient' of federal aid when it merely makes use of a service or facility that receives any federal assistance." *Department of Transportation* v. *Paralyzed Veterans of America*, No. 83-1055 (D.C. Cir. April 26, 1985) (Bork, J., dissenting), slip op. at 1. *See* Petition of Department of Transportation in No. 85-289 at 20-21.

If the airlines' utilization of federally-funded airports does not convert them into federally-assisted programs, neither should hospitals be deemed recipients of federal assistance because they provide services to persons whose medical bills are paid by the government.

> *vision or control over the administration or operation of any such institution,* agency, or person. (Emphasis supplied.)

In other words, even assuming that Medicare were otherwise a relevant nexus to hospitals, Congress has specifically forbidden the federal government from undertaking through that insurance program the activities that it had intended in regard to seriously-ill infants.[22]

c. Medicaid is not an appropriate link to the federal regulation of hospitals.

Medicaid is a medical-assistance program operated essentially by state governments for a variety of impoverished persons including children under grants-in-aid provided by the federal government. 42 U.S.C. § 1396. All states operate Medicaid programs, except Arizona, which operates an alternative program under a demonstration authority. While the monies spent are federal in origin, payments to hospitals are made by each state pursuant to different and specific requirements established by that state. Those requirements involve state-determined payment principles and eligibility criteria. 42 U.S.C. § 1396a. Moreover, as far as the participation of hospitals within the States, nothing in the statute provides for any federal intervention or supervision.

In *Alexander* v. *Choate, supra,* the Court rejected the notion "that the benefit provided through state Medicaid programs is the amorphous objective of 'adequate health care.'" 105 S. Ct. at 722. Instead, the Court noted that "Medicaid programs do not guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs. Instead, the benefit provided through Medicaid is a particular package of health care services . . . ." *Id.*

The Court thus has precluded the very mode of outcome analysis that petitioner would employ here in alleging that

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[22] A similar prohibition of federal interference was enacted under the now-expired Hill-Burton program which provided construction grants. See 42 U.S.C. § 291m.

Medicaid constitutes federal financial assistance of a specific enough nature to allow the regulation of medical care—*i.e.*, the influence over its outcome—in hospitals. In view of *Alexander* v. *Choate*, petitioner's position has been foreclosed. Medicaid simply provides no program-specific basis to regulate medical care in hospitals.[23]

For all of the foregoing reasons, petitioner cannot possibly satisfy section 504's threshold requirement that regulation under it be premised, in this case, upon the identification of a federally-financed program or activity from which hospitals could be shown to have discriminated against seriously-ill infants.[24]

3. Medical treatment decision-making cannot constitute discrimination by hospitals within the plain meaning of section 504.

In the previous sections, respondents have demonstrated that section 504, on its face, cannot furnish authority for the federal regulation of the treatment of seriously-ill infants because those infants are not "otherwise qualified handicapped individuals" and because there is no "program or activity receiving Federal financial assistance" of which hospitals are direct beneficiaries that can be linked to the specific matter that the government sought to regulate. There is yet a final jurisdictional barrier that petitioner cannot surmount, and it is at the very heart of the case. That is the element of discrimination.[25] And rather

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[23] Furthermore, because nothing in any relevant statute or regulation could be said to have given hospitals unambiguous notice prior to their acceptance of Medicare or Medicaid payments that such acceptance would subject them to such conditions, the inadequacy of statutory notice renders those conditions unenforceable. *Pennhurst State School and Hospital* v. *Halderman*, 451 U.S. 1 (1981).

[24] Petitioner therefore acted unlawfully in promulgating a regulation which assumed the existence of federally-financed programs or activities involving hospitals without any factual basis. 5 U.S.C. § 706(2).

[25] Section 504 protects covered individuals from being "excluded from the participation in," "denied the benefits of" or "subjected to discrimination under" federally-financed programs or activities.

Citing statutory and regulatory provisions that require that hospitals not discriminate against alcoholics or drug addicts, petitioner contends

than "requir[ing] little discussion," as petitioner suggests (Brief for Petitioner at 26), the issue is worthy of analysis.

a. Hospitals do not make treatment decisions.

Throughout petitioner's brief, there is a stated view of the authority and function of hospitals that has no basis in law or fact. That view is that hospitals make treatment decisions. See, *e.g.*, Brief for Petitioner at 12, 13, 15 and 45. They do not; treatment choices are, in all cases relevant here, made by the parents of infants in consultation with physicians. Accordingly, it is not possible for a hospital to "exclude from," "deny benefits" to, or "subject to discrimination," as to treatment, a patient who has been admitted to its facilities. Therefore, section 504 cannot be applied to a hospital on the basis of a claim that an infant is being denied a particular course of medical treatment.

Within the network of interrelated responsibilities at an American hospital, it is the individual physician who bears the responsibility for treatment of his or her patients. *See* Joint Commission on Accreditation of Hospitals ("JCAH"), *Accreditation Manual for Hospitals* 84 (1985).[28] American Hospital Association and American Medical Association, *The Report of the Joint Task Force on Hospital*

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that these provisions demonstrate "the application of section 504 to medical treatment decisions . . . ." Brief for Petitioner at 42; *see id.* at 37-39. To the contrary, these provisions were not directed at treatment decisions, but at access. *See* S. Rep. 93-208, 93d Cong., 1st Sess. 14 (1973). Substance abusers had been excluded from some medical facilities because of those persons' arguably disruptive behavior. Congress sought to change that situation, but not to affect the nature of treatment given when such persons were admitted to hospitals. Additionally, the specific inclusion of substance abusers within the coverage of section 504 cannot, as petitioner argues, be taken to encompass a category of persons—infants—who are not mentioned in the inclusive language. If any inference can be made from the provisions cited by petitioner it is that Congress did not intend to expand the coverage of section 504 to medical treatment decisions made as to seriously-ill infants.

[28] Pursuant to the Medicare Act, DHHS recognizes accreditation by JCAH for purposes of determining hospital compliance with the conditions of participation in the Medicare program.

Medical Staff Relationships ("Joint Task Force Report") 13 (1985). Although the hospital's governing board is fundamentally responsible for insuring "the delivery of quality, cost-effective health care to patients in the hospital" (Joint Task Force Report at 10), and although the hospital's organized medical staff "uses its collective professional skills, knowledge, and judgment to provide overall surveillance of the quality and adequacy of medical care provided by individual physicians in the hospital environment" (*id.* at 13), neither the governing board nor the medical staff can assume the individual physician's role or responsibility in the treatment of individual patients. *Id.* at 13.

When a patient, such as a seriously-ill infant, is unable to express his or her preference among treatment options, the decision as to the most appropriate course of treatment resides with the infant's parents in consultation with the treating physician. Indeed, DHHS recognized this role in the April 1985 regulation implementing the Child Abuse Amendments of 1984, stating "the decision to provide or withhold medically-indicated treatment is, except in highly unusual circumstances, made by the parent or legal guardian . . ." 50 Fed. Reg. 14880 (1985). *See also, Parham* v. *J.R.*, 442 U.S. 584 (1979), in which the Court expressed "confidence in the medical decisionmaking process" (*id.* at 612) and recognized the right of parents, in consultation with physicians, to have a mentally-ill child institutionalized, even over the child's objections (*id.* at 604-621); *Matter of Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976) (recognizing appropriateness of family decisions made in consultation with physicians, to remove life support from incompetent daughter); American Hospital Association, The Patient's Choice of Treatment Options 2-3 (1985). DHHS' section 504 regulation, however, which by its terms was applicable solely to hospitals, in its implementation could have achieved its effect only by regulating the professional role and responsibilities of *physicians* vis-a-vis certain of their patients, a responsibility which the hospitals themselves may not assume. Inevitably, the operation of this

regulation intruded upon and impaired the complicated and delicate relationships among physicians, parents and infants. *See* Affidavit of Richard L. Epstein, J.A. 164-65. *See also* Affidavit of Peter A. M. Auld, M.D., J.A. 167-170; Affidavit of Rita Gilman Harper, M.D., J.A. 173-76. Thus, the implementation of the regulation disrupted that which petitioner was seeking to guarantee: the delivery of effective medical care to infants. *See* Affidavit of Paul M. Rosenberg, J.A. 178-182; Affidavit of Norman B. Urmy, J.A. 183-186.

That disruption also emphasized the inappropriateness of attempting to extend section 504 to compel hospitals to alter the course of treatment that the federal government might find objectionable. Because hospitals cannot make the treatment decisions that petitioner would attack as "discriminatory," section 504, by its explicit terms, cannot be applied to hospitals as petitioner seeks to do.

b. Medical treatment decisions cannot constitute discrimination, denial or exclusion within the meaning of section 504.

Drawing upon the facts of the Bloomington "Baby Doe" case, petitioner once more offers the simplistic view rejected by the court of appeals in *University Hospital.*[27] Again, misunderstanding the fact that hospitals cannot make treatment decisions, petitioner argues that if surgery would not be performed on a "handicapped" infant that would be performed on a non-handicapped child, the hospital (not the parent or the physician) would have discriminated against that child in violation of section 504. In rejecting this view, the court of appeals held that "the government has taken an over-simplified view of the medical

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[27] The inapplicability of petitioner's attempts to affect medical treatment by regulating hospitals is further demonstrated by the fact that there is absolutely no evidence of a hospital's refusing to provide services where a parent has consented to an infant's treatment. Nor is there any evidence of a hospital's not standing ready to provide services but for a parent's refusal to consent. Indeed, that is precisely what happened in the Bloomington case. Because hospitals do not have the authority to make treatment decisions, petitioner's regulations were both futile and unnecessary.

decision-making process. Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.' " *University Hospital, supra,* 729 F.2d at 157.

The court's decision comports with current medical knowledge. As recent published testimony before the United States Commission on Civil Rights makes clear, virtually all seriously-ill infants have a number of disabling conditions that must be considered and treated in an interrelated fashion. *See* Protection of Handicapped Newborns: Hearings Before the United States Commission on Civil Rights (1985) ("Civil Rights Commission Hearings") at 7-9, 35-36, 48-50, 55-56 (testimony of Dr. Mildred Stahlman); 13-16 (testimony of the Surgeon General, Dr. C. Everett Koop); 17-19 (testimony of Dr. David McClone). This observation is supported in the general medical literature as well.[28] The court of appeals was thus correct in holding that the discrimination paradigm offered by petitioner is not reasonably related to common medical experience. The more cer-

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[28] *See* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behaviorial Research, *Deciding To Forego Life Sustaining Treatment* ("President's Commission Report") 199-203 (1983); M. Ravitch & K. Welch, *Pediatric Surgery* 464-65 (3d ed. 1979) (surgery to correct tracheoesophageal fistula and factors contributing to increased survival rates); R. Behrman & V. Vaughn, *Nelson Textbook of Pediatrics* (12th ed. 1983) at 295-97 (varieties and causes of Down syndrome); 311 (incidence and causes of various congenital malformations); 414-15 (various viral infections to which neonates may fall prey); 423 (inborn errors of metabolism and the clinical effects, including irreversible damage); 478-79 (Gm2 gangliosidoses—cerebral degeneration and early death); 847-49 (diagnosis and problems of treatment of toxoplasmosis—a parasitic infection which can cause cerebral calcification, psychomotor retardation, convulsions, and hydrocephalus or microcephaly); 908-909 (causes and treatment of intestinal malrotation and ileal or jejunal obstruction of the intestine); 1482-88 (causes and treatment of adrenocortical hyperfunction leading to genital abnormalities); and 1560-70 (causes and treatment of various defects of the nervous system including anencephaly, encephalocele, spina bifida with myelomeningocele, spina bifida occulta, holoprosencephaly, hydranencephaly, lissencephaly, microcephaly and hydrocephalus).

tain event is that the child's condition is what gives rise to the need for a physician to consider treatment and the parent to make the decision as to whether it should be provided and, if so, to what extent.

The testimony and writings of physicians, including the United States Surgeon General,[29] uniformly describe medical care decisions as being made along a continuum of many cases of varying complexity and severity, but all of which can be characterized by the fact that there is a patient who has an illness or condition, almost always several, whose treatment potentialities must be evaluated by those with the authority to make choices. Hospitals do not have that authority. These determinations may be assessed to be effective or ineffective, or even medically-appropriate or inappropriate,[30] but they have nothing to do with comparisons to well children, who require no medical judgments. Nor do they have anything to do with "discrimination" under section 504.

Petitioner herself offers considerable support for this conclusion. Petitioner has stated the position that no violation of section 504 would arise with regard to failure to treat an infant so seriously ill that such treatment is "futile" or would "do no more than temporarily prolong the act of dying." 49 Fed. Reg. at 1653, J.A. 123. This position is consistent with the testimony of the Surgeon General and others that it would be medically inappropriate to provide treatment that would cause pain to the patient and which would not significantly ameliorate the patient's condition, even if it temporarily staved off death. *See* Civil Rights Commission Hearings at 24, 33 (testimony of Dr. David McClone); *id.* at 32-33, 48-50 (testimony of Dr. Mildred Stahlman); *id.* at 34 (testimony of Dr. R. Everett Koop).

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[29] *See, e.g.*, Civil Rights Commission Hearings at 13-16 (testimony of Dr. R. Everett Koop); *id.* at 7-9, 35-36, 48-50 (testimony of Dr. Mildred Stahlman).

[30] Some of the mechanisms for these determinations under the aegis of traditional state authority are discussed in Argument II, *infra*, at pp. 43-45.

It is notable that what DHHS is effectively contending is that when a seriously-ill infant reaches a certain level of or combination of defects, the asserted protections of section 504 no longer apply. Moreover, the federal government claims for itself an extensive right to determine when this point has been reached.[31] Section 504, on its face, provides no support for such authority, which fundamentally contradicts traditional American medical decision-making. However, petitioner's assertion of it undoes her postulation of how medical treatment decisions can constitute unlawful discrimination.

If the hypothetical child with Down syndrome, described in petitioner's brief, is being denied surgery solely because of his or her condition, as petitioner suggests, so is the terminally-ill child, who petitioner states does not have to be treated, even though it might be shown that that child's life might be prolonged. Both cases may be reduced to the simplest level, each child having only a single condition or "handicap" and each, according to petitioner's theory, being denied treatment solely because of it. In one case, however, the government would approve the denial, in the other case, it would assert that section 504 had been violated. This contradiction demonstrates two things: that the federal government was seeking to supersede the authority of parents and physicians to make medical decisions; and that a treatment decision as to a seriously-ill infant cannot constitute discrimination with the plain meaning of section 504.[32]

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[31] Although petitioner would require that the medical treatment of seriously-ill infants meet a DHHS-determined "standard of care," petitioner has conceded that "every case must be examined on its individual facts." 49 Fed. Reg. 1654, J.A. 122. It was, indeed, the fact that "no two cases are likely to be the same," that led the court in *University Hospital* to conclude that these cases would burden the courts with "lengthy litigation primarily involving conflicting expert testimony" on issues of "medical judgment." 729 F.2d at 157. *Compare United States* v. *Erika*, 456 U.S. 201 (1982).

[32] This is not to say that section 504 can never be applied to a hospital. Assuming the existence of a hospital program that is specifically assisted with federal funding, a hospital might discriminate if it denied a handi-

B. Because The Legislative History Of Section 504 Is Concerned Entirely With Programs Of Education, Vocational Training and Independent Living, And Contains No Indication That Medical Treatment Decisions Were To Be Addressed, That Legislative History Provides No Basis Of Authorization For The Federal Government To Regulate The Medical Treatment Of Seriously-Ill Infants.

Although the Court need go no further than the plain meaning of section 504's language to hold that the statute was not intended to reach medical treatment decision-making in regard to seriously-ill infants, any ambiguity in the meaning or application of that language may be resolved by a review of the legislative history which demonstrates, as the Second Circuit concluded in *University*

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capped person access to that program if the program is otherwise generally available. In the instant case, there is no question that seriously-ill infants, whether they are viewed as "otherwise qualified handicapped individuals" or not, are being admitted to American hospitals where they become involved in the treatment process. Thus, the regulation that was invalidated below was not directed at guaranteeing access to hospitals but instead at influencing the course of treatment of seriously-ill infants already within hospitals. The court of appeals' decision in that regard is consistent with this Court's holding in *Alexander* v. *Choate, supra.*

Cautioning against an overexpansive reading of section 504, the Court held that the statute was not violated by a state's reduction of paid Medicaid days, even though that reduction might result in a failure to provide handicapped persons with "adequate health care." 105 S. Ct. at 722. The Court therefore held that "Section 504 does not require the State to alter this definition of the benefit being offered simply to meet the reality that the handicapped have greater medical needs." Section 504 therefore guarantees no more than access to the medical decision-making process. "The Act does not, however, guarantee the handicapped equal results . . . ." *Id.; see Southeastern Community College* v. *Davis, supra.*

The court of appeals in *University Hospital* was of the same view, holding that Congress' "primary concern" with regard to section 504 was that the handicapped be afforded *"access* to federally-funded programs and activities." 729 F.2d at 159 (emphasis supplied). *See Lunceford* v. *District of Columbia Board of Education,* 745 F.2d 1577 (D.C. Cir. 1984); *Plummer by Plummer* v. *Branstad,* 731 F.2d 574 (8th Cir. 1984); *Duquette by and Through Duquette* v. *Dupuis,* 582 F. Supp. 1365 (D. N.H. 1984); *Doe* v. *Colautti,* 545 F. Supp. 621 (E.D. Pa., 1978), *aff'd,* 592 F.2d 704 (3d Cir. 1979). Similarly, in *Simkins* v. *Moses H. Cone Memorial Hospital,* 323 F.2d 959 (4th Cir. 1963), *cert. denied,* 376 U.S.

Hospital, "that congress never contemplated that section 504 would apply to treatment decisions of this nature." 729 F.2d at 157. Although the word "health care" was introduced into the statutory language with the 1977 amendments, at no time in any legislative history is the term referred to in any context other than that concerning access.

Congress clearly intended that Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d, *et seq.*, upon which section 504 was patterned, would eliminate the then-statutorily-permitted "separate-but-equal" racial segregation in the admissions policies of federally-assisted hospitals.[33] However, despite a few oblique references to health and medical treatment, the legislative histories of both the Humphrey/Vanik proposal to amend Title VI to cover the handicapped and the Rehabilitation Act of 1973 strongly support the conclusion that those bills essentially were addressed to educational, vocational rehabilitation, and employment opportunities for handicapped individuals.

It should be noted that President Nixon's vetoes of the earlier versions of the Rehabilitation Act were based in part on his concern that they would improperly require the provision of medical services, and it is significant that Congress receded on this issue. Furthermore, when Congress in the 1974 Amendments to the Rehabilitation Act subsequently broadened the definition of "handicapped individual" and stated its intention that section 504 should apply to discrimination against the handicapped with regard to, *inter alia*, "health services," the legislative history of those amendments is confined to the matter of denial of *admission* to Federally-assisted health care institutions and Congress neither stated nor suggested that Section 504 has any applicability to medical treatment decision-making.

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938 (1964), a case which figured prominently in the legislative history of Title VI, neither the plaintiffs nor the court asserted that any remedy other than the elimination of barriers to equal access was appropriate or necessary.

[33] *See* 110 Cong. Rec. 6543 (Humphrey), *quoting Simkins* v. *Moses H. Cone Memorial Hospital, supra*, 323 F.2d at 970 n. 23. *See also* 110 Cong. Rec. 6050 (Javits), 7061-62 (Pastore).

Finally, Congress' enactment of the 1978 Amendments did not, as petitioner contends, constitute a general endorsement of the 1977 Department of Health, Education and Welfare ("DHEW") regulations implementing section 504[34] which applied to the provision of "health services or benefits" (45 C.F.R. §§ 84.51-84.53) and which, in an appendix, addressed the provision of "medical treatment" (45 C.F.R. Part 84, App. A, ¶ 36). As the legislative history to the 1978 Amendments to the Rehabilitation Act makes clear, the only DHEW regulations "codified" by the passage of those Amendments were the procedural regulations governing *enforcement* of rights guaranteed by section 504 which included no more than *access* to health-care services.

1. The Humphrey/Percy/Vanik proposal to amend Title VI.

Subsequent to the enactment of Title VI, Senators Percy and Humphrey and Representative Vanik proposed an amendment to Title VI which would have prohibited discrimination against the handicapped in Federally-assisted programs and activities. This amendment was the ancestor of section 504. *See Alexander* v. *Choate, supra,* 105 S. Ct. at 718, n. 13. Petitioner, quoting out of context certain statements by Senator Humphrey and Representative Vanik in reference to handicapped children and health,[35] suggests that such statements show that the intent "carried forward" into section 504 included an intent to address the medical treatment of seriously-ill infants and that the tenor of such statements "strongly supports" the DHHS regulations concerning such treatment. The full text of the quoted remarks contradicts petitioner's opinion.

The fact that Senator Humphrey and Representative Vanik were in fact addressing no more than adequate education, training, and facilities for handicapped individuals capable of being trained to help themselves, rather than medical treatment (as petitioner claims), is revealed by

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[34] 45 C.F.R. Part 84 (1977).

[35] Brief for Petitioner at 33-34 n. 21.

both the context of the referenced statements [36] and the portions the petitioner omitted therefrom.[37] Similarly, when Senator Humphrey listed "certain examples documenting the need for this legislation," all of his examples concerned *educational opportunities* for handicapped children. *Id.* at

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[36] Thus, the central theme of Representative Vanik's discussion of "babies . . . born with defects" [117 Cong. Rec. 45974 (1971)] was that "[e]ducation and vocation training is perhaps the great equalizer of employment opportunity in that it provides the individual with the most basic tools of any trade." *Id.* And Mr. Vanik concluded by stating that his "proposed legislation will ensure *equal educational and employment opportunities* for the handicapped, by making discrimination illegal in Federally-assisted programs and activities." *Id.* at 45975, emphasis supplied. Furthermore, when Senator Humphrey, on behalf of himself and Senator Percy, introduced his bill (S. 3044) "which has been introduced jointly in the other body by Representative Charles A. Vanik of Ohio as H.R. 12154" (118 Cong. Rec. 526 (1972)), he similarly emphasized his concern with providing special classes and programs for handicapped children, vocational training and similar programs for handicapped persons generally, and with removing the barriers to employment and independent living for the handicapped. *Id.* at 525.

[37] The italicized portions of the statement set forth below indicate the pertinent omissions from the quotation of Senator Humphrey's remarks set forth in the Brief for Petitioner at 33:

> These people have the right to live, to work to the best of their ability —to know the dignity to which every human being is entitled. *But too often we keep children, who we regard as "different" or a "disturbing influence," out of our schools and community activities altogether, rather than help them develop their abilities in special classes and programs. Millions of young persons and adults who want to learn a trade, work like other people, and establish their self-worth through a paycheck, are barred from our vocational training programs and from countless jobs they could perform well . . . . Where is the cost-effectiveness of consigning them to public assistance or "terminal" care in an institution?*
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> *These are people who can and must be helped to help themselves. that this is their constitutional right, is clearly affirmed in a number of recent decisions in various judicial jurisdictions.* Every child—gifted, normal, and handicapped—has a fundamental right to educational opportunity and a right to health. *And we know, for example, that more than one-third of the 6 million persons who are actually retarded today are capable of earning a living and being self-supporting productive members of the community if adequate training and residential facilities are provided for them.*

118 Cong. Rec. 523 (1972), emphasis supplied.

525-26.[38] He nowhere suggested a Federal role concerning medical treatment decision-making with regard to the handicapped. Accordingly, petitioner's suggestion that Senator Humphrey and Representative Vanik intended that the nondiscrimination provisions apply to treatment decisions is unsupportable.

In the Brief Amici Curiae of the American Coalition of Citizens with Disabilities, *et al.* ("ACCD") at 25-26, ACCD argues that Senate Concurrent Resolution 52, 117 Cong. Rec. 42294 (1971), which "call[ed] for a declaration of rights for the mentally and physically handicapped" (*see* 118 Cong. Rec. 11789 (1972) (remarks of Sen. Percy), demonstrates Congress' intent to address medical treatment of the handicapped in the bills at issue.[39] Contrary to ACCD's contention, however, there is no allusion in the legislative history to the Concurrent Resolution's "recognition" of a "right" to medical care, and, as previously discussed, that

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[38] Likewise, when Senator Humphrey subsequently introduced voluminous supporting materials (newspaper articles, editorials, etc.) into the record, the subject of all of these materials was the inadequate education and training programs for handicapped children and adults and the failure of many institutions to provide adequate training or safe and healthful conditions. *See* 118 Cong. Rec. 9495-9501.

[39] In a statement by Senator Percy (the co-sponsor of S. 3044) inserted into the record by Senator Humphrey, Senator Percy referred to Senate Concurrent Resolution 52. 118 Cong. Rec. 526 (1972). Among the many "rights" endorsed in the Concurrent Resolution was "the right to proper medical care and physical restoration and to such education, training, rehabilitation, and guidance as will enable that person to develop his ability and potential to the fullest possible extent, no matter how severe his or her degree of disability." 117 Cong. Rec. 42294. Without referring to medical care, Senator Percy stated that S. 3044 "would realize this commitment [*i.e.*, that of the Concurrent Resolution], guaranteeing the handicapped equal opportunity to education, job training, productive work, due process of law, a decent standard of living, and protection from exploitation, abuse and degradation." 118 Cong. Rec. 526.

Thereafter, in April of 1972, when Senators Percy and Humphrey introduced the bill to amend Title VI to bar discrimination on the basis of handicap in employment, Senator Percy stated that "[w]hile that the Concurrent Resolution was not meant to solve the problems that plague our handicapped citizens, it was an attempt to draw attention to their plight and encourage the solution of their problems." 118 Cong. Rec. 11789.

issue was raised nowhere in the discussion of the proposed amendments. Equally importantly, many other "rights" listed in the Concurrent Resolution clearly are irrelevant to those bills or to section 504.[40] Accordingly, it cannot be asserted that Congress considered or intended to codify a "right" to medical treatment and ACCD's contention is "bootstrapping" in the extreme.

2. The Rehabilitation Act of 1973.

The Rehabilitation Act of *1972,* passed by Congress in that year, was twice vetoed by President Nixon, and the Senate failed to override those vetoes. President Nixon's veto was motivated in part by his concern that certain sections of the legislation "would divert the Vocational Rehabilitation program from its original purposes by requiring that it provide new medical services . . . , a concern . . . that can be approached more effectively within the Medicare program, as existing legislation already provides." 119 Cong. Rec. 24570 (1973) (second veto message). Significantly, as the court observed in *University Hospital,* Congress "was forced to back down" on this issue, and "authorized research projects instead of categorical [treatment] programs . . . ." 729 F.2d at 157.

The meaning and scope of the non-discrimination provision received scant attention during the passage of the 1972 and 1973 Rehabilitation Acts, and most references to the provision simply quoted or restated its terms.[41] The

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[40] *E.g.,* "a right to economic security and to a decent standard of living," a "right to a qualified financial or legal guardian," "a right to live with his or her own family or with foster parents, and to participate with all aspects of community life, and to be provided with appropriate leisure time activities." 117 Cong. Rec. 42294.

[41] *See* 117 Cong. Rec. 45945 (1971); 118 Cong. Rec. 525, 526, 8399, 8894, 11797, 16371, 30681, 30682, 30683, 32280, 32281, 32282, 32294, 32302, 32310, 35155, 35163, 35837 (1972); 119 Cong. Rec. 65, 5862, 5873, 5880, 5915, 6145, 7114, 7136, 7153, 18127, 24562, 24569, 24571, 24580-81, 24586-89, 29628, 29633 (1973), *See also University Hospital,* 729 F.2d at 157 ("this provision . . . was never a matter of controversy. Consequently, there is little discussion of it in the volumes of legislative history that were generated.").

legislative history of the 1973 Act, for example, describes Section 504 as "a provision proclaiming a policy of nondiscrimination against otherwise qualified handicapped individuals with respect to participation and/or access to any program which is in receipt of Federal financial assistance." S. Rep. No. 318, 93rd Cong., 1st Sess. 50, *reprinted in* 1973 U.S. Code Cong. & Ad. News 2076, 2123.[42] Nowhere in the legislative history of the 1972 and 1973 Rehabilitation Acts is there any suggestion that the nondiscrimination provision would address medical treatment decision-making.[43]

3. Rehabilitation Act Amendments of 1974

As the court emphasized in *University Hospital*, "[t]he post-enactment legislative history also indicates both that congress was primarily concerned with affording the handicapped access to federally-funded programs and activities, and that congress never envisioned that HEW (or HHS) would attempt to apply section 504 to treatment decisions." 729 F.2d at 159.[44]

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[42] Similarly, the section-by-section analysis simply states that section 504 "prohibits discrimination, exclusion or denial of benefits to otherwise qualified handicapped individuals by any program or activity receiving Federal financial assistance." 1973 U.S. Code Cong. & Ad. News at 2143. *See also* 119 Cong. Rec. 5882 (1973) (remarks of Sen. Alan Cranston); 119 Cong. Rec. 24586-87 (remarks of Sen. Jennings Randolph).

[43] Particularly misleading in this regard is petitioner's claim (Brief for Petitioner at 34, n. 21) that Representative Vanik's post-enactment references to the ancient Spartans "touch on" the medical treatment of seriously-ill infants. On the contrary, Representative Vanik's comments referred solely to the elimination from the final bill of his proposal for educational assistance for handicapped children, and not to medical treatment of any handicapped person. (119 Cong. Rec. 18137).

[44] Thus, although it is emphasized in the legislative history of the Rehabilitation Act Amendments of 1974, S. Rep. No. 1297, 93d Cong., 2d Sess. 37-41, *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6388-91, that Congress "clearly" intended that section 504 not be limited to employment and vocational rehabilitation issues, and that such issues are "irrelevant to many forms of potential discrimination covered by section 504" (*id.* at 6388), the Senate Report contains no definition or discussion of "health services" except for a hypothetical example of "handicapped persons who may be denied admission to Federally-assisted nursing homes on the basis

4. Rehabilitation, Comprehensive Services and Developmental Disabilities Act Of 1978 (1978 Amendments To Rehabilitation Act).

Petitioner contends that DHEW's 1977 regulations (45 C.F.R. Pt. 84) show a "firmly established" administrative application of Section 504 to medical treatment decisions (Brief for Petitioner at 42), and that Congress' 1978 amendments to the Rehabilitation Act constituted "a general endorsement of" DHEW's 1977 regulations. Brief for Petitioner at 42, *citing* S. Rep. No. 890, 95th Cong., 2d Sess. 19 (1978).

Congress in 1978 added Section 505(a)(2) of the Act (92 Stat. 2984) to provide that "[t]he remedies, procedures, and rights set forth in Title VI . . . shall be available to any person aggrieved by any act or failure to act by any recipient of Federal assistance or Federal provider of such assistance under Section [504]." This new subsection was addressed to the procedures, remedies, and rights pertaining to *enforcement* of section 504, rather than to the substantive rights protected by section 504,[45] as this Court

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of their handicap" (*id.* at 6389), an issue of *access* to services. See n. 32, *supra*. Accordingly, while Congress apparently was concerned that handicapped persons might be denied access to Federally-assisted medical facilities, the legislators did not consider or address medical treatment decisions within such facilities.

[45] The Senate Report stated the committee's understanding that "the regulations promulgated by [DHEW] with respect to procedures, remedies, and rights under Section 504 conform with those promulgated under Title VI. Thus, this amendment [Section 504(a)(2)] codifies existing practice as a specific statutory requirement." S. Rep. No. 890, 95th Cong., 2d Sess. 19 (1978). The DHEW Section 504 regulation [45 C.F.R. § 84.61] which "conforms" to the regulations promulgated under Title VI in fact simply *incorporated* the enforcement rights and procedures provided in DHEW's Title VI regulations. As stated in 45 C.F.R. § 84.61, "[t]he procedural provisions applicable to title VI of the Civil Rights Act of 1964 apply to this part. These procedures are found in §§ 80.6 through 80.10 and Part 81 of this Title." The Title VI regulations thus incorporated into the Section 504 enforcement provision include provisions governing: compliance information (§ 80.6); conduct of investigations (§ 80.7); procedures for effecting compliance (§ 80.8); hearings (§ 80.9); decisions and notices (§ 80.10); and "Practice and Procedure for Hearings Under Part 80 of this Title" (Part 81).

recognized in *Consolidated Rail Corp.* v. *Darrone,* 104 S. Ct. at 1255. Accordingly, and directly contrary to the petitioner's claim that the Court has understood this action by Congress in 1978 [*i.e.*, enactment of Section 505(a)(2)] "to constitute a general endorsement of HEW's section 504 regulations" (Brief for Petitioner at 42), Congress made no such general endorsement and neither considered nor addressed HEW's suggestion that the reach of section 504 might extend to medical treatment.[46]

Accordingly, as the court correctly held in *University Hospital,* "[t]he legislative history . . . indicates that Congress never contemplated that section 504 would apply to treatment decisions of this nature." 729 F.2d at 157.

C. DHHS' Current Interpretation Of Section 504 Should Be Accorded No Deference In Evaluating The Statute And Its History Because The Agency's View Is Neither Long Nor Consistently Held.

While courts often defer to an agency's interpretation of the statute it administers, "[i]n order for an agency interpretation to be granted deference, it must be consistent with the congressional purpose." *Morton* v. *Ruiz,* 415 U.S. 199, 237 (1974) (citations omitted). In addition, to be entitled to any weight, such agency interpretations must also be *consistently held. United States* v. *National Associ-*

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[46] This suggestion appeared in an appendix to its regulation concerning non-discrimination in the provision of Federally-assisted health services. *See* 45 C.F.R. Pt. 84, App. A, ¶ 36. There is likewise no suggestion that Congress, in enacting Section 505(a)(2), considered or addressed DHEW's regulations concerning the treatment of alcoholics and drug addicts. Thus, although 45 C.F.R. § 84.53 provides that Federally-assisted medical facilities "may not discriminate in admission or treatment against a drug or alcohol abuser or alcoholic who is suffering from a medical condition, because of the person's drug or alcohol abuse or alcoholism," that regulation is based upon statutory authority other than Section 504 [42 U.S.C. (Supp. I) 290dd-2(a)]. And although both the Attorney General and the Secretary have expressed the opinion that Section 504 would impose a similar requirement (*see* 43 Op. Att'y Gen. No. 12 (1977) at 10; 45 C.F.R. Pt. 84, App. A, ¶ 37), it cannot be said that Congress in 1978 considered DHEW's regulations or observations concerning the treatment of alcoholics and drug addicts.

ation of Securities Dealers, Inc., 422 U.S. 694, 718 (1975); *Morton* v. *Ruiz*, 415 U.S. at 237; *Trafficante* v. *Metropolitan Life Insurance Co.*, 409 U.S. 205, 210 (1972). Petitioner's recent assertion of section 504 authority regarding seriously-ill infants does not meet these standards.

Petitioner contends that the invalidated DHHS regulation governing medical treatment of seriously-ill infants (45 C.F.R. § 84.55, J.A. 111-126) is consistent with prior regulations promulgated by the Department to implement section 504, and that the "Baby Doe" regulation simply articulates (albeit in an expanded form) the manner in which DHHS previously had interpreted and enforced section 504 and the regulations implementing that statute. Brief for Petitioner at 2-3, 39-42, 40-46.

Contrary to these contentions, however, the Department's regulations implementing section 504 from the outset have been addressed to insuring that handicapped persons have access to federally-assisted health institutions, and were promulgated upon the recognition of important differences between handicap and race which make it impossible to apply the same approach to eliminating discrimination under section 504 and Title VI. As previously referenced, the Secretary in 1976 stated that "[h]andicapped persons may require different treatment in order to be afforded equal access to federally assisted programs and activities, and identical treatment may, in fact, constitute discrimination." 41 Fed. Reg. 20296 (1976).

Furthermore, on the only occasion (prior to 1982) when the Department considered whether it possessed authority under section 504 to promulgate regulations addressing a patient's right to medical treatment, the Secretary specifically concluded that DHHS did not possess such authority. *See* 41 Fed. Reg. 20296-97, 41 Fed. Reg. 29559 (1976). Accordingly, as the court concluded in *University Hospital*:

> [T]he regulatory history of section 504 is inconclusive. HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW . . . . In determining whether Congress intended section 504 to apply to treatment decisions involving

> defective newborn infants, we therefore lack the benefit of an administering agency's longstanding, consistent interpretation to which we otherwise might have looked for guidance.

729 F.2d at 154, citations omitted.[47]

II. In The Absence Of Any Clear Statement Of Congressional Intent, Congress Cannot Be Presumed To Have Superseded The Traditional Role Of The States In Dealing With Child Protection and Medical Treatment.

Virtually all of the *amici curiae* supporting petitioner ask this Court, on alleged public policy grounds, to imply that section 504 reaches medical treatment decisions affecting seriously-ill infants.[48] However, federal entrance into the field of child protection, which traditionally has been left to the regulation of the States, may not be presumed in the absence of an unequivocal manifestation of congressional intent. Not only has Congress expressed no such intent, it recently reaffirmed the traditional role of the States through the Child Abuse Amendments of 1984. Seriously-ill infants are, therefore, not without significant protection. The well-entrenched state mechanisms are working, and coupled with advances in medical education and resource deployment, the needs of seriously-ill infants are demonstrably being met by hospitals and by physicians.

A. The Federal Government Lacks Authority Under Section 504 To Supersede The Traditional Role Of The States In Dealing With The Medical Treatment Of Seriously-Ill Infants.

In the absence of a clear congressional mandate, long-established precedent precludes implication of federal entry into a field traditionally occupied by the States. In *Apex Hosiery Co.* v. *Leader*, 310 U.S. 469 (1940), for example,

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[47] Petitioner cites a single instance in which in 1980, before the regulatory effort at issue, DHHS asserted section 504 authority to investigate the medical treatment of an infant in a hospital. Brief for Petitioner at 44 n. 35. However, rather than demonstrating any such authority, the hospital did no more than to fulfill its state law obligations.

[48] *See, e.g.*, Brief *Amici Curiae* of the American Coalition of Citizens With Disabilities, *et al.*, at 4-5.

the Court emphasized that "[t]he maintenance in our federal system of a proper distribution between state and national governments of policy authority and of remedies private and public for public wrongs is of far-reaching importance. An intention to disturb the balance is not lightly to be imputed to Congress." 310 U.S. at 513 (1940). *See also Jones* v. *Rath Packing Co.*, 430 U.S. 519, 525 (1977), *quoting United States* v. *Bass*, 404 U.S. 336, 349 (1971); *FTC* v. *Bunte Bros., Inc.*, 312 U.S. 349, 354-55 (1941). Accordingly, the Court "in construing legislation . . . has disfavored in-roads by implication" upon the States' traditional police powers. *Palmer* v. *Commonwealth of Massachusetts*, 308 U.S. 79, 84 (1939).

Petitioner claims that section 504 authorizes DHHS to investigate and intervene in treatment decisions concerning seriously-ill infants, even if relevant state agencies are taking or have taken an active role in such cases. *See* 48 Fed. Reg. 30849 (1983). However, while "state statutes and regulations may be superseded by validly enacted regulations of federal agencies . . . ," *Katharine Gibbs School, Inc.* v. *FTC*, 612 F.2d 658, 667 (2d Cir. 1979), it is also the case that "[w]here the field which Congress is said to have preempted has been traditionally occupied by the States, . . . 'we start with the assumption that the historic police powers of the States were not to be superseded unless that was the clear and manifest purpose of Congress.' " *Jones* v. *Rath Packing Co., supra*, 430 U.S. at 525, *quoting Rice* v. *Santa Fe Elevator Corp.*, 331 U.S. 218, 230 (1947) (other citations omitted).

No party disputes that all of the States traditionally and actively have occupied the field of protection of children against abuse and neglect, and that the State agencies and mechanisms that deal with those matters have authority to take action where necessary medical care is being denied. On the other hand, there is nothing that can be called a clear statement of congressional intention—as to section 504 or any other federal enactment—for the federal government to enter the field in any way other than to assure that the State agencies are accomplishing their purposes.

The protection of children is, of course, a traditional and fundamental power of the States acting in their role as *parens patriae*. *See Prince* v. *Commonwealth of Massachusetts*, 321 U.S. 158, 166-67 (1944). Even in the absence of statutory authority, a state court of equity "has both the power and responsibility to care for and protect all those persons who, by virtue of some legal disability, are unable to protect themselves." *Custody of a Minor*, 375 Mass. 733, 379 N.E. 2d 1053, 1060 (Mass. 1978).[49]

Furthermore, every state (including the District of Columbia) has enacted legislation making child abuse and neglect a crime and imposing on physicians and hospital personnel requirements of mandatory reporting of suspected instances of such abuse or neglect.[50] Forty-eight states and the District of Columbia include the failure to provide medical care specifically within the scope of proscribed conduct,[51] and the remaining two states have interpreted their statutes [52] as applicable to cases involving

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[49] In appropriate circumstances, the States may exercise their power to order medical treatment of a minor despite parental objection. *See, e.g., Wright* v. *DeWitt School Dist.*, 238 Ark. 906, 385 S.W.2d 644 (1965); *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980); *In re Ivey*, 319 So. 2d 53 (Fla. Dist. Ct. App. 1975); *Jefferson* v. *Griffin Spalding County Hosp. Auth.*, 247 Ga. 86, 274 S.E.2d 457 (1981); *People ex rel. Wallace* v. *Labrenz*, 411 Ill. 618, 104 N.E.2d 769 (1952), *cert. denied*, 344 U.S. 834 (1952); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978); *In re Brooklyn Hosp.*, 45 Misc. 2d 914, 258 N.Y.S.2d 621 (N.Y. Sup. Ct. 1965); *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970); *In re Clark*, 185 N.E.2d 128 (Ohio 1962); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942).

[50] These statutory provisions are listed in the Appendix to this Brief, at 1a-2a.

[51] These statutory provisions are listed in the Appendix to this Brief, at 3a.

[52] Neb. Rev. Stat. § 43-247(1)(3)(a) (1984); N.D. Cent. Code §§ 27-20-02(5) (1981).

failure to provide medical care.[53] Finally, where an investigation reveals that a child is being mistreated, state law authorizes the appropriate agency to initiate proceedings to bring the child within the jurisdiction of a court, take the child into protective custody, and, where appropriate, initiate criminal prosecutions.[54]

Given the longstanding involvement of the States in protecting children, and the comprehensiveness of the statutory approaches to that goal, and given the utter lack of anything approaching a clear pronouncement that Congress intended that the federal government do anything other than support the States, the Court should not allow DHHS to regulate by petitioner's fiat.

B. In The Child Abuse Amendments, Congress Built Upon Existing State Protective Mechanisms In Order To Reaffirm Both The Rights Of Seriously-Ill Infants And The Need To Avoid Unreasonable Governmental Intervention Into Parental Responsibilities And The Practice Of Medicine.

When Congress recently addressed the issue of medical treatment decisions concerning seriously-ill infants in the Child Abuse Amendments of 1984, it did so in a manner recognizing and amplifying the States' traditional authority in the area and assigning the federal government to do no more than to assure that the States would carry out their responsibilities.[55] This approach was selected instead of alternatives including amendment of section 504 to am-

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[53] *See, e.g., In re Interest of M.W., et al.*, 217 Neb. 325, 348 N.W.2d 861 (1984) (failure, *inter alia*, to administer medication, bring children to doctor); *In the Interest of R.W.B.*, 241 N.W.2d 546 (N.D. 1976) (failure, *inter alia*, to secure proper medical care for child).

[54] *See, e.g., State* v. *Clark*, 5 Conn. Cir. Ct. 699, 261 A.2d 294 (1969); *Bradley* v. *State*, 79 Fla. 651, 84 So. 677 (1920); *Eaglen* v. *State*, 249 Ind. 144, 231 N.E.2d 147 (1967); *Commonwealth* v. *Edelin*, 371 Mass. 497, 359 N.E.2d 4 (1976); *State* v. *Staples*, 126 Minn. 396, 148 N.W. 283 (1914); *Matthews* v. *State*, 240 Miss. 189, 126 So. 2d 245 (1961); *State* v. *Stehr*, 92 Neb. 755, 139 N.W. 676 (1913), *aff'd on rehearing*, 94 Neb. 151, 142 N.W. 670 (1913).

[55] See pp. 46-47, *infra*.

plify its coverage to medical treatment decisions and to seriously-ill infants.[56]

When it enacted the Child Abuse Amendments, Congress was fully aware of the courts' uniform refusals to hold that section 504 authorized federal intervention in medical treatment decisions. *See* S. Rep. No. 246, 98th Cong., 2d Sess. 5-8 (1984). Although there was considerable attention given to this issue, Congress decided not to resolve the question but implicitly, through its neutrality language,[57] to leave it to the courts to do so in pending or future cases. This congressional forebearance, in recognition of an intense dispute over the issue of section 504 jurisdiction, offers convincing evidence that a majority in both Houses recognized at least that Congress had not manifested a clear intention for the federal government to get into a field so heavily occupied by the States. This Court, therefore, should not hold that Congress intended to legislate more broadly than its expressions in either the Child Abuse Amendments or the legislative history of section 504.

In their Brief *Amicus Curiae*, Senator Hatch and Representative Murphy incorrectly argue that AHA contends that the Child Abuse Amendments demonstrate "congressional hostility toward protection of disabled infants under section 504." Brief Amicus Curiae of Hon. Orrin G. Hatch and Austin J. Murphy, Members of Congress, In Support of Petitioner at 8-9. To the contrary, Congress explicitly stated its neutrality on the point. Congress did not, as Senator Hatch and Congressman Murphy imply, express support for DHHS' section 504 regulation.

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[56] The courts had suggested that Congress might do this. *United States* v. *University Hospital*, *supra*, 729 F.2d at 161, *American Academy of Pediatrics* v. *Heckler*, *supra*, 561 F. Supp. at 401-402.

[57] Sec. 127(a) of the Child Abuse Amendments (98 Stat. 1754) provides:

> No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

The point is that Congress had the opportunity to state that section 504, in amended form or otherwise, covered the medical treatment of seriously-ill infants, but it chose not to do so. Instead, Congress, with the active participation of AHA and others in the hearings and conference process, did no more than to act to ensure state compliance.

In the preface to its final rule implementing the Child Abuse Amendments, 45 C.F.R. Part 1340, as added by 50 Fed. Reg. 14887-92 (April 15, 1985), DHHS conceded that the Amendments reflect Congress' clear intent to "build upon existing mechanisms at the state level" (50 Fed. Reg. 14881) in developing "an effective and workable program to assure the provision of appropriate medical care to disabled infants." 50 Fed. Reg. 14879. As the Agency also recognized, the statute represents a "careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable government intervention into the practice of medicine and parental responsibilities." *Id.*

Finally, DHHS recognized that the States' role rendered unnecessary a confidential 24-hour federal telephone hotline specified in DHHS' invalidated section 504 regulation (45 C.F.R. § 84.55(b), 49 Fed. Reg. 1651, J.A. 112-114) for reporting the suspected withholding of treatment from seriously-ill infants "[b]ecause the Act so clearly places responsibility for implementation on State CPS [Child Protective Service] agencies . . . ." 50 Fed. Reg. at 14884.

Although the legislative history of section 504 does not show that Congress intended that statute to apply to the medical treatment of seriously-ill infants, and despite the Agency's recognition that the Child Abuse Amendments represent a balanced and meticulously crafted congressional determination of the most appropriate allocation of authority for addressing such issues, petitioner and others now ask the Court to hold that section 504 provides implicit authorization for DHHS to assume the role Congress designated for the States in the Child Abuse Amendments. Not only is such a federal role without support in the language and history of section 504, it is unnecessary as well.

C. There Is No Need For Federal Involvement In Medical Treatment Decision-Making Concerning Seriously-Ill Infants.

Although petitioner and her supporters argue that the withholding of necessary treatment from newborns is occurring frequently throughout the country, the facts do not support this assessment. For example, although the government's energetic investigation of hotline tips and complaints under the interim final rule resulted in considerable disruption and adversely affected patient care in subject hospitals, *none* of those investigations—49 in all—resulted in a finding of "discrimination," as petitioner uses the term. *See* 49 Fed. Reg. at 1649. Furthermore, even the Surgeon General of the United States, and other strong supporters of DHHS' section 504 regulation, concede that medical education has improved, resources are better developed and deployed, and relatively few inappropriate treatment decisions are made. *See Protection of Handicapped Newborns: Hearings Before the United States Commission on Civil Rights* (1985), at 51-52 (Testimony of Dr. C. Everett Koop).

A similar conclusion was reached by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the "Commission"). As the Commission found, "treatments are rarely withheld when there is a medical consensus that they would provide a net benefit to a child." President's Commission Report at 217. Furthermore, having stated the principle that "permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant" (*id.* at 218), the Commission emphasized that the available studies and testimony before the Commission show that "decision-making about seriously-ill newborns . . . usually adheres to the precepts outlined in this chapter." *Id.* at 223, n. omitted.

> Of the more than three million babies born each year in the United States, tens of thousands are born pre-

> maturely or with congenital anomalies and many of them would die quickly if not treated. Yet it is rare for treatment not to be provided when it is predicted to provide a means of remedying the medical problem: the cases when approval for such treatment is denied are few enough to be newsworthy. While very disturbing, they may be inevitable in a society that treasures personal and familial autonomy. Moreover, there is little reason to think that greater control by state officials, in the name of protecting the helpless, would actually be warranted only if it clearly saved more lives. Furthermore, such steps would raise problems of governmental intrusion into private matters in many cases where no better decision could be made.

Id. at 209 n. 51.

In summary, in the Child Abuse Amendments, the only federal statute specifically addressing the medical treatment of seriously-ill infants, Congress recognized and built upon the States' traditional functions and comprehensive remedies to protect such infants' interests and to avoid unreasonable governmental intrusion into the practice of medicine. In contrast, DHHS intervention in this area under the alleged authority of section 504 is unauthorized and unnecessary in light of the array of broad investigative, protective, remedial, and prosecutorial powers of the States and the evidence demonstrating that hospitals and physicians are acting responsibly.

CONCLUSION

The American Hospital Association and other responsible members of the health services community recognize that the care of seriously-ill infants is a matter of the greatest public import. AHA has participated actively in helping to assure that the needs of such infants will be met, drawing upon the resources of the traditional parent/physician relationship, education and review capabilities of hospitals, and the authority of the States to act in egregious cases. The fact that the interests of seriously-ill infants are important cannot, however, justify petitioner's unprecedented intrusion into medical treatment decision-mak-

ing under the purported authority of section 504 of the Rehabilitation Act of 1973.

Respondents submit that the plain meaning of the terms of section 504 are inconsistent with petitioner's invalidated regulatory effort, and that Congress has never stated a clear intent for the federal government to have such authority. For these reasons, the judgment of the court of appeals should be affirmed.

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Nov. 4, 1985

APPENDIX

APPENDIX

STATE STATUTORY PROVISIONS REQUIRING REPORTING OF SUSPECTED CHILD ABUSE OR NEGLECT

Ala. Code §§ 26-14-1 - 26-14-13 (1977 & Supp. 1985); Alaska Stat. §§ 47.17.010 - 47.17.070 (1984 & Supp. 1985); Ariz. Rev. Stat. Ann. § 13-3620, § 36-2282 (Supp. 1984-85); Ark. Stat. Ann. §§ 42-807 - 42-819 (1977 & Supp. 1985); Cal. Penal Code §§ 11165-11174 (Deering Supp. 1985); Colo. Rev. Stat. §§ 19-10-101 - 19-10-116 (1978 & Supp. 1984); Conn. Gen. Stat. Ann. §§ 17-38-17-38f (West 1975 & Supp. 1985); Del. Code Ann. tit. 16, §§ 901-909 (1983); D.C. Code Ann. §§ 6-2101-2107 (1981); Fla. Stat. Ann. §§ 415.502-415.514 (West Supp. 1985); Ga. Code Ann. § 19-7-5 (1982); Hawaii Rev. Stat. §§ 350-1 - 350-7 (1976 & Supp. 1984); Idaho Code §§ 16-1601 - 16-1629 (1979 & Supp. 1985); Ill. Ann. Stat. ch. 23, §§ 2051-2061.7 (Smith-Hurd Supp. 1985); Ind. Code Ann. §§ 31-6-11-1 - 31-6-11-22 (West 1979 & Supp. 1985); Iowa Code Ann. §§ 232.67-232.77 (West 1985); Kan. Stat. Ann. §§ 38-716 - 38-724 (1981); Ky. Rev. Stat. Ann. § 199.335 (Baldwin Supp. 1984); La. Rev. Stat. Ann. § 14:403, §§ 40:1299.36.1-40:1299.36.3 (West 1974 & Supp. 1985); Me. Rev. Stat. Ann. tit. 22, §§ 4011-4017 (Supp. 1984-85); Md. Fam. Law Code Ann. §§ 5-701 - 5-710, §§ 5-901 - 5-912 (1984 & Supp. 1985); Mass. Ann. Laws ch. 119, §§ 51A-51G (1975 & Supp. 1985); Mich. Stat. Ann. §§ 25.248(1)-25.248(16) (Callaghan 1984); Minn. Stat. Ann. § 626.556 (1983 & Supp. 1985); Miss. Code Ann. §§ 43-21-353 - 43-21-355 (Supp. 1984); Mo. Ann. Stat. §§ 210.110 - 210.174 (Vernon Supp. 1985); Mont. Code Ann. §§ 41-3-201 - 41-3-208 (1983); Neb. Rev. Stat. §§ 28-711 - 28-727 (1979 & Supp. 1984); Nev. Rev. Stat. §§ 200.501 - 200.5085 (1981 & Supp. 1983 & Supp. 1984); N.H. Rev. Stat. Ann. §§ 169-C:29 - 169-C:40 (Supp. 1983); N.J. Stat. Ann. §§ 9:6-8.8-9:6-8:20 (West 1976 & Supp. 1985); N.M. Stat. Ann. §§ 32-1-13 - 32-1-16 (Supp. 1985); N.Y. Soc. Serv. Law §§ 411-418 (McKinney 1983 & Supp. 1984-85 & Supp. July 1985); N.C. Gen. Stat. §§ 7A-542 - 7A-552 (1981 & Supp. 1983); N.D. Cent. Code §§ 50-25.1-01 - 50-25.1-13 (1981 & Supp. 1985); Ohio Rev. Code Ann. § 2151.42.1 (Page Supp. 1983); Okla. Stat. Ann. tit. 21, §§ 845-848 (West 1983 & Supp. 1984-85); Or. Rev. Stat. §§ 418.740-774 (1983); Pa. Stat. Ann. tit. 11, § 2201-2213 (Purdon Supp. 1985); R.I. Gen. Laws §§ 40-11-1 - 40-11-16 (1984 & Supp. 1984); S.C. Code Ann. §§ 20-7-500 - 20-7-560 (1985); S.D. Codified Laws §§ 26-10-1 - 26-10-18 (1984 & Supp. 1985); Tenn. Code Ann. §§ 37-1-401 - 37-1-413 (1984 & Supp. 1985); Tex. Fam. Code Ann. §§ 34.01-34.08 (Vernon 1974 & Supp. 1985); Utah Code Ann. §§ 78-3b-1 - 78-3b-15 (Supp. 1983 & 1985); Vt. Stat. Ann. tit. 33, §§ 681-689 (Supp. 1984); Va. Code §§ 63.

1.248.1-63.1.248.17 (1980 & Supp. 1985); Wash. Rev. Code Ann. §§ 26.44.010-26.44.900 (Supp. 1986); W. Va. Code §§ 49-6A-1 - 49-6A-10 (1980 & Supp. 1985); Wis. Stat. Ann. § 48.981 (Supp. 1985); Wyo. Stat. §§ 14-3-201 - 14-3-215 (1977 & Supp. May 1985).

STATE STATUTORY PROVISIONS INCLUDING FAILURE TO PROVIDE MEDICAL CARE WITHIN PROHIBITION OF CHILD ABUSE OR NEGLECT

Ala. Code § 26-14-1 (1977); Alaska Stat. § 47-10.010(a)(2)(B) (Supp. 1985); Ariz. Rev. Stat. Ann. § 13-3620(A) (Supp. 1984-85); Ark. Stat. Ann. § 42-807(c) (Supp. 1985); Cal. Penal Code § 11165(c)(1) and (2) (West 1985); Colo. Rev. Stat. § 19-1-103(20)(d) (1978); Conn. Gen. Stat. Ann. § 46b-120 (West 1985); Del. Code Ann. tit. 31, § 301 (1975); D.C. Code Ann. § 16-2301(9)(B) (1981); Fla. Stat. Ann. § 39.01 (27) (West Supp. 1985); Ga. Code Ann. § 15-11-2(8)(A) (Supp. 1984); Hawaii Rev. Stat. § 350-4 (1976), § 587-2 ["Guidelines" (19)(A)] (Supp. 1984); Idaho Code § 16-1602(n)(1) (Supp. 1985); Ill. Rev. Stat. ch. 37, § 702-5(c) (Supp. 1985); Ind. Code Ann. § 31-6-4-3(a)(1) (West Supp. 1985); Iowa Code Ann. §§ 232.2.6.e (West 1984); Kan. Stat. Ann. § 38. 722(a) (1981); Ky. Rev. Stat. § 199.011(c) (1985); La. Rev. Stat. Ann. § 14-403(B)(4) (West Supp. 1985); Me. Rev. Stat. Ann. tit. 22, § 4002 (6)(B) (1981); Md. Pub. Safety Code Ann. § 35A (1973), Md. Fam. Law Code § 5-701(g)(2) (1984); Mass. Ann. Laws ch. 273, § 1 (Michie/ Law. Co-op. 1980); Mich. Comp. Laws Ann. § 722.622(c) (West 1984); Minn. Stat. § 626.556(2)(c) (Supp. 1985); Miss. Code Ann. § 43-21-105(1)(i) (1981); Mo. Rev. Stat. § 210.110(5) (1983); Mont. Code Ann. § 10-503 (1983); Nev. Rev. Stat. § 200.5011(1) and (3) (1983); N.H. Rev. Stat. Ann. § 169-C:3(b) and (c) (Supp. 1983); N.J. Rev. Stat. § 9:6-8.9(d) (1976); N.M. Stat. Ann. § 30-6-1(A)(2) (Supp. 1983); N.Y. Soc. Serv. Law § 371.4-a(i)(A) (McKinney 1983); N.C. Gen. Stat. § 7A-517(21) (1981); Ohio Rev. Code Ann. § 2151.03 (Page 1976); Okla. Stat. Ann. tit. 21, § 852 (West 1983); Or. Rev. Stat. § 418.740(1)(b) (1983); Pa. Stat. Ann. tit. 11, § 2203 (Purdon Supp. 1985); R.I. Gen. Laws § 40-11-2(2)(d) (Supp. 1983); S.C. Code Ann. § 20-7-490(c)(3) (Law Co-op. 1983); S.D. Codified Laws Ann. § 26-8-6(4) (1984); Tenn. Code Ann. § 37-1-102(9)(d) (Supp. 1984); Tex. Fam. Code Ann. §§ 12.04 (3), 34.01 (Vernon 1975); Utah Code Ann. § 78-3a-2(17)(c) (Supp. 1983); Vt. Stat. Ann. tit. 33, § 682(3)(c) (1984); Va. Code § 63.1-248.A.2 (1980); Wash. Rev. Code Ann. §§ 26.44.010, 26.44.020(3) and (12) (Supp. 1985); W. Va. Code § 49-1-3(g)(1)(A) (1985); Wis. Stat. Ann. § 48.981(1)(d) (West Supp. 1984-85); Wyo. Stat. § 14-6-201(a)(xvi) (A) (Supp. 1984). With nine exceptions, the foregoing statutes specifically encompass or address parental failure to provide medical or health care. However, the statutes for the nine "non-specific" jurisdictions (Connecticut, District of Columbia, Georgia, Idaho, Massachusetts, New Hampshire, Oregon, Pennsylvania, and Washington) all clearly address denials of medical treatment as a form of abuse or neglect because those statutes provide that provision of treatment by a licensed spiritual practitioner (*e.g.*, Christian Scientist) shall not in itself be deemed abuse or neglect of a child.

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No. 84-1529 (19)

IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF FOR THE RESPONDENTS THE AMERICAN MEDICAL ASSOCIATION, THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES, AND THE AMERICAN ACADEMY OF FAMILY PHYSICIANS, *ET AL.*

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QUESTIONS PRESENTED

When it enacted Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, did Congress authorize the Secretary of the Department of Health and Human Services:

(a) to investigate and regulate directly whether parents have made reasonable treatment decisions on behalf of their impaired newborn children;

(b) to supplant state officials by investigating and determining directly whether physicians have violated their state law duty under state child abuse and neglect statutes to report to state authorities known or suspected instances of parental "neglect;" and

(c) to investigate and regulate directly whether physicians' treatment decisions involving severely impaired newborn infants are appropriate under federal "504" standards of medical care which the Secretary will establish in individual cases?

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

BRIEF FOR THE RESPONDENTS AMERICAN MEDICAL ASSOCIATION, *ET AL.*

INTRODUCTION

This case presents the question of whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, authorizes direct federal investigation and regulation of individual treatment decisions made by parents and health care providers relating to severely impaired newborn infants. The question of what sort of medical treatment, if any, should be given to severely impaired newborns is "one of the most difficult and sensitive medical and ethical problems facing our society" and federal "intervention into the difficult medical and human decisions that must be made in the delivery rooms and newborn intensive care units of our hospitals involves a *profound change* in the manner in which these decisions . . . are made." [1]

[1] *American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 395, 396, 403 (D.D.C. 1983) (Gesell, J.) (emphasis supplied).

Neither the 1973 statute nor its legislative history mentions, much less authorizes, a direct federal role in these sensitive decisions in which the infant's interests have historically been protected within the state law framework governing parent-child and physician-patient relationships. Nonetheless, until enjoined by the courts below, petitioner, the Secretary of the Department of Health and Human Services ("HHS"), had undertaken direct, intrusive and overbearing federal investigations—including 17 on-site inquiries by federal "Baby Doe" squads—in the days, even hours, immediately following the birth of a child, during a period of maximum stress for families. The focus of these HHS investigations has not been on discrimination between handicapped and non-handicapped but rather on alleged "medical neglect" of an impaired infant when its parents refuse to authorize treatment—a subject historically regulated exclusively under state child abuse and neglect laws. In not one of those 49 harmful federal investigations reported in HHS's Final Regulation on this subject (J.A. 11) did HHS find any violation of Section 504. (J.A. 96-106).

Respondents American Medical Association ("AMA") *et al.*[2] seek affirmance of the judgment below which enjoined HHS (a) from implementing the Final Regulation with respect to individual treatment decisions by parents and health care providers *and* (b) from investigating such decisions in the absence of a specific regulation on the subject, as HHS had done in all 49 of its reported inquiries. When parents *do not* consent to treatment for their seriously ill infant, HHS may not convert state law issues of possible child neglect into federal issues of discrimination against the handicapped in order to put pressure on parents through direct federal investigations, as

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[2] This case, *American Medical Association, et al.* v. *Heckler*, was brought separately and then consolidated in the District Court with *American Hospital Association, et al.* v. *Heckler* after the Court of Appeals decision in *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984) (Pet. App. 4a). Respondents in each case are briefing and arguing separately in this Court.

it has tried to do in the regulatory regime invalidated below. As the Court of Appeals held, HHS has no authority to investigate and regulate directly either parental treatment decisions or physicians' duties under state law to report possible parental neglect to state authorities.

When parents *do* consent to treatment for their severely ill infant, physicians provide it. HHS has not cited, and cannot cite, even a single example when physicians have failed to provide treatment to impaired newborns after parental consent. HHS may not use this wholly implausible and highly misleading hypothetical example—which has not been the focus of its regulatory efforts, but which it emphasizes in this Court—to retain its power to conduct intrusive investigations in neonatal intensive care units.

STATEMENT

The Secretary's statement of the case (HHS Br. 2-11) is either inaccurate or incomplete in virtually every important respect. It largely ignores the medical, ethical and state law framework which is crucial to understanding this action. It also gives a completely distorted view of HHS's efforts to date by omitting *any* discussion of HHS's numerous investigations of parental decisionmaking, including its oppressive actions in the controlling *University Hospital* case.

(1) *The State Law Framework.* State law provides protection to impaired newborns when parents do not consent to treatment on their behalf. Under the law of all 50 states, parents, as the individuals best suited to protect their child, have the ultimate responsibility for making decisions about treatment for seriously ill newborns. Their decision is final except in the most extreme case when a state court has determined that a decision by the parents not to authorize treatment constitutes "medical neglect" of a child. 50 Fed. Reg. 14880 (1985). All 50 states also have child protective service agencies which are responsible for investigating reports of child abuse and neglect by parents—including "medical neglect"—and addressing the sensitive issue of when government should

institute court actions to remove the parents as decision-makers for the child. *Id.* at 14878.[3] In addition, all 50 states have mandatory statutory provisions requiring physicians to report known or suspected instances of medical neglect by parents to state authorities. Civil sanctions, criminal penalties or both may be imposed on physicians for failing to discharge these state reporting duties.[4]

State law also protects minor patients in their relationship with physicians when parents do consent to treatment. Of course, without parental consent, a physician may not treat a minor patient because treatment without such consent is a battery. *See* note 23, *infra*. But, it is a fundamental rule of state law and medical ethics that, once parental consent to treatment has been given, then physicians have a legal duty to provide appropriate medical care until the physician-patient relationship is terminated by giving the parents due notice and an opportunity to obtain other care. Under the state law doctrine of patient abandonment, if physicians withdraw before these conditions are satisfied, then they are liable for damages and subject to state disciplinary action.[5]

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[3] *See generally* Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645 (1977); Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975).

[4] *See generally* Besharov, *The Legal Aspects of Reporting Known and Suspected Child Abuse and Neglect*, 23 VILL. L. REV. 458 (1977-1978). Only physicians, not hospitals, are authorized under state law to provide medical treatment. *See* AMA & AHA, *Report of the Joint Task Force on Hospital-Medical Staff Relationships* (1985). For purposes of discussion, however, we will assume that, under the Final Regulation, the duties of physicians and hospitals (which are customarily the recipients of federal health care funds) are synonymous. *See* 49 Fed. Reg. 1637 (1984) (J.A. 65).

[5] *See* 1 D. Louisell & H. Williams, MEDICAL MALPRACTICE ¶¶ 4.12, 8.08 (rev. ed. 1984). *See also* AMA, CURRENT OPINIONS OF THE JUDICIAL COUNCIL § 8.10 (1984) (similar duty under canons of medical ethics). Medical licensing statutes also provide sanctions, including revocation or suspension of a license, for patient abandonment. *See, e.g.*, CAL. BUS. & PROF. CODE § 2234 (West Supp. 1985); D.C. CODE ANN. § 2-1326 (1981); ILL. REV. STAT. ch. 111,

(2) *The Medical and Ethical Context.* As a 1983 Presidential commission reported, the birth of an infant with severe mental or physical impairments is often an unexpected and traumatic event for parents, who are confronted with the necessity of making difficult life or death treatment decisions with little or no advance warning. In such circumstances, treatment itself may cause the infant great pain and suffering.[6] These trying cases may test the limits of medical science and present physicians with highly complex and often uncertain choices about what treatment, if any, is appropriate to recommend. Although physicians can in some cases predict with a relative degree of confidence that a particular course of treatment is likely to be beneficial or futile, there is a significant area of uncertainty (exacerbated by rapid and continuing advances in medical techniques) in which the results and consequences of a given course of treatment are simply unpredictable and may, in fact, change as the condition of the severely impaired newborn changes. *President's Commission Report* at 198, 217. Three types of medical conditions have been the subject of the most widespread medical and ethical discussion about areas of certainty and uncertainty: spina bifida, Down's Syndrome, and low birth-weight or premature infants.[7] As the *President's Commission Report* noted (at p. 220):

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§ 4433 (Smith-Hurd Supp. 1984-85); N.Y. EDUC. LAW § 6509 (McKinney Supp. 1984).

[6] *See* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 215-216 (1983) (*"President's Commission Report"*); R. Stinson and P. Stinson, THE LONG DYING OF BABY ANDREW (1983).

[7] Spina bifida with meningomyelocele is a congenital disorder characterized by an open spinal column and exposure of neural tissue and, in most cases, hydrocephalus (an abnormally large fluid collection in the brain), which can cause varying (and unpredictable) degrees of impairments, including mental retardation and paralysis. Down's Syndrome is a rare chromosomal disorder involving varying degrees of mental retardation and an increased incidence of sometimes correctable congenital defects. Premature

> Much of the difficulty in these [ambiguous] cases arises from factual uncertainty. For the many infants born prematurely, and sometimes for those with serious congenital defects, the only certainty is that without intensive care they are unlikely to survive; very little is known about how each individual will fare with treatment. Neonatology is too new a field to allow accurate predictions of which babies will survive and of the complications, handicaps, and potentials that the survivors might have. (Footnote omitted).

Nonetheless, despite this uncertainty in some cases, physicians are required by basic principles of medical ethics to provide all available medical treatment which is expected to benefit these severely impaired infants and to which parents consent.[8]

To address the difficult medical and ethical issues which can be raised by the birth of a severely impaired child, the *President's Commission Report* (at pp. 225-227; J.A. 189-192), repudiated a direct federal role like the one advanced by the Secretary and, instead, recommended the voluntary formation of infant care review committees to deal directly with the fundamental problem in this sensitive area: parental lack of information

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or low birth-weight infants, by far the largest category of cases involving difficult decisions about treatment of newborns, often suffer from a host of different but related disorders, many of them life-threatening. *See* A. Rudolph, Pediatrics 140-148, 243-245, 1594-1596 (17th ed. 1982); W. Nelson, R. Behrman & V. Vaughan, Textbook of Pediatrics 134-136, 342-353, 1561-1562 (12th ed. 1983).

[8] The AMA and other medical organizations have made clear that medical treatment which is expected to benefit the infant should always be provided and that, in determining what treatment will benefit the infant, the anticipated burdens of an impaired child on the family and on society should not be the basis for decision. *See, e.g.*, AMA, CURRENT OPINIONS OF THE JUDICIAL COUNCIL § 2.14 (1984); 49 Fed. Reg. 1622 (1984) (J.A. 12-13) (quoting *Principles of Treatment of Disabled Infants* adopted by several major medical and disability groups).

and perspective. *Id.* at 227.[9] Despite the trying circumstances in which choices must be made, parents have been able to make appropriate treatment decisions that are in the best interests of their child. *Id.* at 209 & n.51 ("rare" for parents not to act appropriately).

(3) *HHS's Intrusive Regulatory Regime: Parents As Targets.* HHS's brief mischaracterizes its regulatory pronouncements, ignores its intrusive investigative efforts and fails to describe any "problem" involving individual treatment decisions for impaired newborns which justifies a direct, intrusive federal role.

a. *HHS's Regulatory Pronouncements.* The regulatory approach reflected in the Final Regulation is the product of several rounds of official notices and interim or proposed rules published by HHS since 1982. These pronouncements reveal inconsistent and contradictory interpretations of Section 504 with respect to the three types of decisions by parents or health care providers which are at issue in this case. This regulatory history shows that the central focus of the Secretary's regulatory activities, despite contrary assertions to this Court, has been the *decision of parents not to authorize certain treatment* for their impaired newborns. The Secretary's attempt to investigate the state law *duties of health care providers to report* known or suspected instances of parental neglect was only conceived *after* the Secretary was forced to acknowledge that parental decisions not authorizing treatment could not be regulated under Section 504. Until its brief to this Court, *"non-treatment" decisions by health care providers themselves,*

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[9] *See President's Commission Report* at 227-228 (J.A. 191-192). Medical groups have made similar proposals. *See e.g.*, AMA, Judicial Council Report, *Guidelines for Ethics Committees in Health Care Institutions*, 253 J.A.M.A. 2698 (1985). These committees may be comprised of physicians, nurses, ethicists, clergy, social workers, lawyers and representatives of disability groups. At present, many hospitals with intensive care units for neonates have special review processes, including infant care review committees, for these difficult cases. 50 Fed. Reg. 14887 (1985).

when parents have given consent, have not been of any concern to HHS because such decisions never occur: HHS has never cited an instance when parents have consented to medically indicated treatment and physicians have not then provided it.

i. *The 1982 Notice.* On May 18, 1982, the Secretary issued a "notice" to health care providers stating that Section 504 applied to treatment decisions involving severely impaired newborns. 47 Fed. Reg. 26027 (1982) (J.A. 127). The Notice was clearly aimed at parents' decisions not to authorize treatment because it was explicitly addressed to the widely publicized "Baby Doe of Indiana" case, where parents had withheld consent to life-sustaining surgery and the hospital had promptly referred the matter to the appropriate state agency and courts for decision under the state's child neglect laws.[10] In this 1982 Notice, the Secretary further stated that, in cases where parents refused to authorize medically indicated treatment for their impaired newborn child, Section 504 required hospitals *to discharge the infant from the hospital* so as not to acquiesce in the parents' "discriminatory" decision.[11] The Notice made no mention of a provider's duty under state law to report instances of parental neglect to state authorities nor was there any

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[10] *See* HHS Br. 2 & n.1. In that case, the parents of a newborn with Down's Syndrome refused to authorize surgery to repair a blocked esophagus. The case was nonetheless referred to the hospital, which sought immediate judicial review. The state court decided that the parents had made a reasonable decision among treatment options. *See* 49 Fed. Reg. 1630 (1984) (J.A. 39) (comments of state court judge who decided case). The county prosecutor then brought a second action and a second state court judge also refused to find parental neglect. The infant then died. *See In re Infant Doe*, No. GU 8204-004A (April 12, 1982), *writ of mandamus dismissed sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind. May 27, 1982); J. Lyon, PLAYING GOD IN THE NURSERY 21-39 (1985).

[11] This position was roundly criticized. *See, e.g.*, Fost, *Baby Doe and Federal Funding: Putting Hospitals on Notice*, 12 HASTINGS CENTER REPORT 5, 7 (1982) (implementation of such a practice would be "gruesome").

hint that it was addressed to the situation in which physicians or hospitals refuse to provide treatment to which the parents had consented.

ii. *Interim Final Rule of 1983.* Less than one year later, HHS issued an "interim final rule" which was again aimed at *parents'* decisions not to consent to treatment on behalf of their newborn children. 48 Fed. Reg. 9630 (1983). The Interim Rule did not suggest that providers are required under Section 504 to refer cases of alleged parental medical neglect to state authorities. Instead, the Interim Rule, in complete disregard of controlling law in all states, required physicians and hospitals to provide needed medical treatment to impaired newborns regardless of the parents' treatment decision. *Id.*[12] On April 14, 1983, a district court declared the Interim Rule invalid under the Administrative Procedure Act (5 U.S.C. §§ 551 *et seq.*) because it had been issued without proper notice and comment procedures, and because HHS had arbitrarily and capriciously failed to consider "many highly relevant factors." [13]

iii. *The Final Regulation of 1984.* Following the invalidation of the Interim Rule, the Secretary on July 5, 1983, proposed a new rule, 48 Fed. Reg. 30846 (1983), which she adopted in final form with minor changes on January 12, 1984, 49 Fed. Reg. 1622 (1984) (J.A. 11) (the "Final Regulation"). The Final Regulation con-

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[12] *See American Academy of Pediatrics, supra,* 561 F. Supp. at 401 (statements of HHS counsel at oral argument) (quoted at Pet. App. 23a). There was also no suggestion that hospitals or physicians were not providing medically indicated treatment to impaired infants after parents had consented to such treatment.

[13] *American Academy of Pediatrics, supra,* 561 F. Supp. at 399. Among the many critical factors ignored or inadequately considered by HHS were: the disruptive effects on ongoing treatment of newborns caused by "the sudden descent of [federal] 'Baby Doe' squads on the scene"; the problems of ignoring parental choices about a child's "best interests"; and the fact that the administrative record failed to disclose "a widespread denial of proper newborn care such as would justify the type of regulation selected." 561 F. Supp. at 399-400.

tains four mandatory provisions: (i) each recipient hospital must post a notice with a 24-hour, toll-free "hotline" number for callers to use in reporting to HHS suspected violations of Section 504 relating to newborns; (ii) expedited HHS access to medical records is authorized; and (iii) expedited compliance actions, including referral of cases to the Justice Department, is authorized. 45 C.F.R. §§ 84.55(b), (d), (e) (J.A. 112-116). The last mandatory provision (iv) authorizes HHS to investigate directly whether hospitals and physicians are discharging their state law duty to report instances of parental neglect to state authorities. *See* 45 C.F.R. § 84.55(c) (J.A. 114-115) and pp. 25-27, *infra*.

When issuing the Final Regulation, HHS made a major, explicit concession and announced an entirely new theory of the applicability of Section 504 to treatment of impaired newborns. Contrary to the position espoused only months before in the Interim Rule, HHS in the preambles to both the proposed and Final Regulation at last explicitly conceded that, absent a state court order, only parents are authorized to make the ultimate treatment decisions on behalf of impaired newborns and that these parental decisions not to consent to treatment, no matter how "discriminatory," are outside the scope of Section 504. 48 Fed. Reg. 30848 (1983); 49 Fed. Reg. 1631 (1984) (J.A. 43-44). Nonetheless, despite this fundamental concession, the Final Regulation was still by its terms aimed at parents. *See* pp. 23-24, *infra*.

The Secretary also articulated a new Section 504 theory that, when parents withhold consent to treatment, HHS may investigate whether health care providers have discharged their duties to report cases of parental neglect to the appropriate state authorities, as required by state law. 48 Fed. Reg. 30848 (1983); 49 Fed. Reg. 1631, 1653 (1984) (J.A. 44, 122). The Secretary formally abandoned her previous Section 504 theory that, when parents did consent, providers had to treat the infant over the parents' objection or to discharge the infant from the hospital. The hypothetical issue which the Secretary em-

phasizes almost exclusively in this Court—whether Section 504 applies to "non-treatment" decisions by health care providers after parents have consented to such treatment—was not addressed in the Final Regulation nor in the supporting HHS statements.

b. *HHS's Actual Investigations.* In the preamble to the Final Regulation, the Secretary described the results of 49 separate cases in which, *without authorization by a specific regulation relating to impaired infants*, she investigated reports of suspected violations of Section 504 in the treatment of impaired newborns. 49 Fed. Reg. 1646-1649 (1984) (J.A. 96-106).[14] Not one of these cases has resulted in a finding of discriminatory withholding of medical care. Virtually all of these direct federal investigations—which were conducted within days, even hours, of the birth of the child—were aimed at decisionmaking *by parents.* In not one of these reported investigations did HHS investigate, much less find, that physicians had failed to refer cases of suspected medical neglect to state authorities. Nor was there even a hint that a physician or hospital had refused to provide a newborn infant treatment to which the parents had consented.

The futility of the Secretary's intrusive investigations, however, was not for want of trying. Of the 49 cases, fully 17 involved on-site investigations. Moreover, in over three quarters of these on-site investigations, HHS apparently made no use of qualified medical consultants, and so HHS employees, as opposed to medical experts, purported to judge the reasonableness of the complex treatment decisions at issue. Significantly, in only four

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[14] Because the Interim Rule of March 1983 had been struck down almost immediately and the proposed rule of July 1983 had no operative effect, virtually all these investigations were undertaken pursuant to the Secretary's claimed inherent authority under Section 504 and the general Section 504 regulation of 1977, 42 Fed. Reg. 22676 (1977), and not pursuant to a specific regulation relating to severely impaired infants. *See* HHS Br. 3, 44 (HHS claims inherent authority under Section 504 and general 1977 regulation to act in absence of specific regulation on impaired infants).

of the cases is there even any mention of coordination with the relevant state child protective service agency, which the Secretary has claimed she will work with closely. HHS Br. 7.[15]

HHS's own record of investigatory and enforcement activity also reveals, on its face, the significant harms that its regulatory approach has caused parents, impaired newborn infants and health care providers. *See* 49 Fed. Reg. 1632 (1984) (J.A. 47-48) (HHS's description of asserted harms of investigations and failure to show those harms do not occur). Often prompted by nothing more than anonymous telephone "tips," HHS "Baby Doe squads" descended on hospitals at all hours of the day and night, demanding to see confidential patient records, interrogating nurses, physicians and other hospital staff and, in some cases, asserting the right to examine the physical condition of the involved newborn infant.[16] As the facts of *University Hospital* illustrate graphically, *see* pp. 21-22, *infra*, the Secretary's investigatory actions had a devastating impact on the parents of the child being investigated, by subjecting them to harassing challenges to their fitness to act as decisionmakers for their child, threatening them with potential criminal liability, and embroiling them in unwanted and damaging publicity, all at a time of great emotional anguish and pressure.

Moreover, as a direct result of these investigations, critical ongoing treatment of impaired newborn infants was significantly delayed or disrupted as HHS investiga-

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[15] The preamble and interpretative guidelines to the Final Regulation provide general HHS policy on the conduct of investigations. *See* 49 Fed. Reg. 1633 (J.A. 48) (any doubts to be resolved in favor of on-site HHS investigation); *id.* 1634 (J.A. 52) (no commitment to have medical consultants present in such investigations); *id.* 1654 (J.A. 124) (HHS must itself investigate all complaints within 24 hours).

[16] *See, e.g.*, J. Lyon, PLAYING GOD IN THE NURSERY 42-44 (1985); *American Academy of Pediatrics, supra*, 561 F. Supp. at 399-400; Strain, *The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 NEW ENG. J. MED. 443 (1983).

tors monopolized patient charts and records and diverted the medical staff from its important health care functions.[17] This drain on hospital resources impaired the delivery of care to all patients and aroused unnecessary confusion, anxiety and fear among other parents and their families.[18]

(4) *The Decisions Below.* a. *University Hospital.* In November, 1983, *after* the state courts of New York had refused to intervene and *after* the state child protective service agency had determined there was no medical neglect by the parents, HHS and the Department of Justice nonetheless prosecuted a suit against University Hospital asserting, under Section 504, the right to examine the medical records of an impaired newborn infant (known only as Baby Jane Doe), whose parents had withheld consent to certain surgery and then refused to give HHS access to the infant's medical records. The District Court, on November 17, 1983, granted summary judgment against the government, holding that the hospital's failure to provide surgical treatment was the result of the parents' decision and not discrimination within the meaning of Section 504 and that, in any event, the par-

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[17] *See, e.g.*, J. Lyon, PLAYING GOD IN THE NURSERY 42-44 (1985); Affidavit of Richard L. Epstein ¶ 9 (J.A. 164-165); Affidavit of Peter A.M. Auld, M.D. ¶ 18 (J.A. 170-171); Affidavit of Rita G. Harper, M.D. ¶ 15 (J.A. 176). The AMA *et al.* submitted uncontested affidavits in support of their motion for summary judgment in this case. In her defense, the Secretary did not submit *any* testimonial evidence on medical issues. *See also* Affidavit of Paul M. Rosenberg (J.A. 178); Affidavit of Norman B. Urmy (J.A. 183) (harmful effects of inquiries in Rochester, N.Y. and Nashville, Tenn.).

[18] *See, e.g.*, Affidavit of Peter A.M. Auld, M.D. ¶¶ 12, 17 (J.A. 169-170); Affidavit of Rita G. Harper, M.D. ¶ 15 (J.A. 176). In addition, there is a significant risk that the arrival of federal Baby Doe squads will lead to painful and futile overtreatment which could injure not just the particular child being investigated but also other seriously ill children by depriving them of scarce places in hospital neonatal intensive care units. *See, e.g.*, Fost, *Baby Doe: Problems and Solutions*, 1984 ARIZ. ST. L.J. 637, 639; Affidavit of Peter A.M. Auld, M.D. ¶ 13 (J.A. 169).

ents' treatment decision had in all respects been reasonable. *United States* v. *University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983). On February 23, 1984, the Court of Appeals affirmed on broader grounds, 729 F.2d 144 (Pet. App. 4a), holding that Section 504 does not "apply to treatment decisions involving defective newborn infants." (Pet. App. 40a). The Secretary declined to petition this Court for review of the Court of Appeals' decision in *University Hospital*.

b. *The Instant Case.* The Final Regulation was promulgated by the Secretary on January 12, 1984, while the *University Hospital* case was pending before the Court of Appeals. On March 12, 1984, the AMA *et al.* filed the instant action in the United States District Court for the Southern District of New York. (J.A. 129). On June 11, 1984, the District Court, under authority of *University Hospital*, issued a final judgment which (a) enjoined HHS from implementing the Final Regulation with respect to treatment decisions by parents and providers in individual cases involving impaired newborns and (b) enjoined HHS from otherwise investigating and regulating such decisions in the absence of a specific regulation on the subject, as HHS had done in its 49 investigations reported before publication of the Final Regulation. (Pet. App. 50a-52a). The Court of Appeals, also relying on the controlling effect of *University Hospital*, summarily affirmed the judgment in a two paragraph order. (Pet. App. 3a).[19]

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[19] Although she had lost in the District Court, the Secretary moved in the Court of Appeals for summary affirmance of the judgment striking down her regulatory regime, claiming that the earlier decision in *University Hospital* (which involved an HHS investigation of a single family) made plenary appellate review unnecessary. Although stating they were ultimately entitled to affirmance, the AMA *et al.* opposed summary disposition on the ground that, because HHS was clearly going to seek review in this Court, a fuller treatment of the issues relating to the Secretary's regulatory efforts would aid Supreme Court consideration. *See* J.A. 9 (docket entry). Accordingly, the AMA *et al.* will argue for affirmance on grounds similar to, but, in certain respects, distinct from, the reasoning of

SUMMARY OF ARGUMENT

Neither the express language of Section 504 nor its legislative history nor the general Section 504 regulation promulgated by HHS in 1977 mentions, let alone authorizes, direct federal involvement in the sensitive and complex issue of providing appropriate treatment in individual cases to severely impaired newborns. Nonetheless, since 1982, the Secretary has taken two types of actions asserting her authority to intrude directly in this most sensitive area of parent-child and physician-patient relations historically governed within a state law framework. She has issued notices and regulations, and she has investigated individual cases directly.

(A) Both HHS's regulatory pronouncements and its investigations have been aimed at instances where *parents do not consent to treatment* for their severely impaired infant. They have thus been aimed at a problem, not of discrimination between handicapped and non-handicapped, but at possible "medical neglect" in individual cases when parents do not authorize treatment for severely impaired newborns. The vexing question of when government should interfere with parents' choices for their infants in these complex, often tragic situations has historically been left to state authority under child abuse and neglect statutes. The related and equally vexing question of when physicians or hospitals should come between parents and their infant children and report parents for known or suspected neglect to state authorities has also been governed by these state statutes. In both its regulatory pronouncements and its actual investigations, HHS has unlawfully tried to turn these state law issues surrounding possible parental neglect into federal issues of discrimination against the handicapped in order to put direct federal pressure on parents through intrusive investigations. The judgment below declared this effort unlawful and

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the Court of Appeals in *University Hospital. See, e.g., Chevron U.S.A., Inc.* v. *NRDC*, 104 S. Ct. 2778, 2781 (1984); *Black* v. *Cutter Laboratories*, 351 U.S. 292, 297 (1956).

enjoined HHS from investigating and regulating individual treatment decisions by parents or providers either under the Final Regulation or under HHS's inherent Section 504 authority. In support of that judgment, respondents AMA *et al.* seek two related holdings barring HHS from intruding directly into state law issues of parental neglect.

First, the Secretary is not authorized by Section 504 to investigate and regulate parents' treatment decisions on behalf of their severely impaired newborns. The Secretary has changed her initial position and has now explicitly conceded that she has no authority under Section 504 to regulate parents directly. She has, thus, implicitly conceded that the judgment of the Court of Appeals in *University Hospital*, barring her from investigating parents who do not authorize treatment, was correct. Nonetheless, a holding of this Court is necessary, because *even after* stating in July 1983 that she had no authority to investigate non-treatment decisions of parents directly, the Secretary in November 1983 launched the oppressive pursuit of Baby Jane Doe's parents that resulted in the *University Hospital* decision. *See* Part I, *infra*.

Second, the Secretary has no authority under Section 504 to investigate and determine directly, before state executive and judicial officials have acted, whether health care providers have violated their state law duties to report known or suspected parental neglect to state authorities. The Secretary's theory here is so far beyond the scope of Section 504 that she barely attempts to defend it in her brief—and for good reason because it has not a shred of support in either the language or legislative history of Section 504. Moreover, this contorted interpretation violates basic rules of construction: it authorizes intrusive federal investigations which totally duplicate state responsibilities and thus constitute a forbidden "fundamental modification" of how health providers operate; it is not based on HHS's finding of a "particularly significant problem"; and it is not the product of the clear statement of congressional intent which

is necessary when the federal government attempts to regulate concurrently in an area historically left to the states. In sum, it simply cannot be that a health care provider could be held by HHS to have violated Section 504 for failing to discharge a *state law* reporting duty when there has been no final state determination by responsible state officials that state law has been violated. *See* Part II, *infra*.

(B) HHS's regulatory pronouncements and actual investigations have never been concerned with the wholly hypothetical case where *parents do consent to treatment* for their severely impaired infant but physicians refuse to provide it. In her brief to this Court, however, the Secretary has systematically distorted her regulatory statements, studiously ignored her actual investigations and misleadingly attempted to defend her actions on the basis of just such a hypothetical case—a case which bears no relationship to the regulatory regime invalidated below or to the world of medical practice. But HHS's attempt to retain intrusive investigative power in this area based on a hypothetical case is demonstrably unlawful.

Respondents AMA *et al.* thus also respectfully request this Court to hold that decisions by physicians in individual cases not to treat severely impaired infants are outside the scope of Section 504. There is no factual or rational basis under the Administrative Procedure Act for HHS regulation in this area. If parents consent to treatment for their impaired infants, physicians provide it. Despite HHS's development of a voluminous administrative record from 1982-1984, the Secretary has *never found or cited a single case* in which a physician has refused to provide treatment to a severely handicapped infant after the infant's parents have consented to such treatment. Moreover, neither the language nor legislative history of Section 504 evidences any Congressional intent to authorize direct HHS regulation of the "reasonableness" of physician decisions according to federal "504" standards of medical care established by the Secretary or to authorize an HHS investigation, before state

authorities have acted, of whether patient "abandonment," an area of medical practice traditionally regulated by the states, has occurred. *See* Part III, *infra.*

(C) By rendering these requested rulings and by thus invalidating HHS's actions against parents and health care providers in this most sensitive and complex area, this Court would not, of course, impair in any way Congress' authority in the future to amend Section 504 if it felt that the problem of appropriate treatment for severely impaired newborn infants warranted direct federal investigation and regulation of parental and provider decisions in individual cases. At issue is nothing more than the discretionary action of a single executive department, not a law of Congress. In this regard, it should be stressed that in the fall of 1984—the only time Congress addressed the question of what federal response to this complex issue is appropriate—Congress refused to authorize HHS's direct federal investigation and regulatory role in individual cases which had been invalidated earlier that year in this case. Instead, Congress used a state grant program and the existing state child protective service agencies to address the issue. In so doing, the sponsors of the law explicitly stated that HHS was prohibited under the Amendments from investigating treatment decisions in individual cases or from establishing federal treatment standards.[20] *See* pp. 47-48, *infra.*

ARGUMENT

The interests of severely impaired newborn infants are protected by their parents, by their physicians, by hospitals, by infant care review committees, by state child protective service agencies and by state courts. The question presented by this case is whether the Congress intended to authorize an additional level of federal involvement immediately after the birth of a severely impaired child and thus meant to empower the Secretary of HHS

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[20] *See* Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984); 130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984) (letter from Sen. Hatch to Sen. Weicker); HHS Br. 45 (no direct federal duties for providers created by 1984 Amendments).

to investigate and regulate directly the three decisions at issue in this case—decisions by parents not to consent to treatment, decisions by physicians when parents do not consent, and decisions by physicians when parents do consent. The answer mandated by the language of Section 504, its legislative history, sound principles of statutory construction and the Secretary's own concessions is clearly "no." [21]

I. THE SECRETARY HAS NO AUTHORITY TO INVESTIGATE AND REGULATE TREATMENT DECISIONS BY PARENTS ON BEHALF OF THEIR IMPAIRED NEWBORNS.

The historic right of parents in consultation with health care professionals to make treatment decisions for their minor children is bottomed on state common law and on the federal constitutional right of privacy.[22] As the Secretary recently stated:

> The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian. *Parents are the decision makers concerning treatment of their disabled infant, based on the advice and reasonable medical judgment of their physician.*

50 Fed. Reg. 14880 (1985) (emphasis supplied). Thus, absent a *state* court finding of medical neglect, final legal responsibility for making decisions about appropriate treatment of seriously ill newborns is vested exclusively in parents.[23]

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[21] The relationship between the three requested holdings and the judgment of the Court of Appeals is discussed at n.60, *infra*.

[22] State law has always recognized the parents' inherent right to make medical decisions on behalf of their children. *See, e.g., In re Hofbauer*, 65 App. Div. 2d 108, 411 N.Y.S.2d 416 (1978), *aff'd*, 47 N.Y.2d 648, 393 N.E.2d 1009 (1979); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942). Parental autonomy to make decisions for their children is also protected under the Constitution. *See, e.g., Wisconsin* v. *Yoder*, 406 U.S. 205 (1972); *Pierce* v. *Society of Sisters*, 268 U.S. 510 (1925); *Meyer* v. *Nebraska*, 262 U.S. 390 (1923).

[23] *See* pp. 3-4, *supra*. A physician or hospital is guilty of battery if surgery is performed on an infant without parental consent. *See,*

A. HHS Concedes That Parents' Decisions Are Not Within The Scope Of Section 504.

In both the July 1983 proposed regulation and the January 1984 Final Regulation, the Secretary conceded that parental decisionmaking is outside the scope of Section 504. In the preamble to the Final Regulation, the Secretary stated: "Section 504 applies only to programs or activities receiving federal financial assistance; *it does not apply to decisions made by parents.*" 49 Fed. Reg. 1631 (1984) (J.A. 43) (emphasis supplied). Similarly, in the interpretative guidelines to the Final Regulation, the Secretary stated unequivocally: "Section 504 and the provisions of this part *are not applicable to parents (who are not recipients of Federal financial assistance).*" *Id.* at 1653 (J.A. 122) (emphasis supplied).[24] *See also* 48 Fed. Reg. 30848-30850 (1983); HHS Br. 5.

B. HHS's Efforts Have Nonetheless Been Aimed Almost Exclusively At Parents' Treatment Decisions.

Despite HHS's concession in July 1983 and January 1984, its regulatory regime has unmistakably been aimed at parents' decisions involving treatment for their severely impaired newborns. Indeed, the "Baby Doe of Indiana" case, which gave rise to the 1982 Notice and all subsequent regulations in this area, involved a decision by parents not to authorize treatment for their child, as the Secretary now explicitly acknowledges for the first time. HHS Br. 2.[25] The 1982 Notice, the 1983 Interim Rule,

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e.g., W. Prosser & W. Keeton, HANDBOOK OF THE LAW OF TORTS § 18, at 116 (5th ed. 1984).

[24] In light of HHS's concessions, the argument by analogy in the *University Hospital* dissent—that "denial of medical treatment to an infant because the infant is black is not legitimated by parental consent"—is clearly in error. (Pet. App. 44a). Regardless of the race, color, creed or impairment of an infant, health care providers have no authority to operate on a child without parental consent or without a court order removing the parent as decisionmaker for the child. Neither Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d *et seq.*, nor Section 504 alters this fundamental rule.

[25] *See* note 10, *supra*. In each of her regulatory pronouncements in this area, as well as in her petition (Pet. 2-3, 17, 20, 22), the

the 1983 proposed rule and the 1984 Final Regulation have all in significant respects been aimed directly at parents' decisions. *See American Academy of Pediatrics, supra*, 561 F. Supp. at 400 ("primary purpose" of interim rule "to prevent parents" from making decisions), 401 (same). Most importantly, virtually all of the 49 investigations reported by HHS in the preamble to the Final Regulation have been aimed directly at parental decisions. *See* pp. 11-13, *supra*.

In fact, the oppressive actions of the Secretary in *University Hospital*—which have been conspicuously absent from her description of that case in this Court (Pet. 8-9; HHS Br. 9-11)—conclusively demonstrate that the purpose of the Secretary's regulatory approach is to interfere with parental decisions not to authorize treatment. After Baby Jane Doe was born with multiple birth defects on October 11, 1983, her parents decided not to consent to certain surgery following consultation with "several physicians, nurses, religious advisors, a social worker, and members of their family." (Pet. App. 6a). The state courts of New York rejected the claim of a third party, unrelated to Baby Jane Doe, seeking appointment of a guardian *ad litem* and an order directing that surgery be performed.[26]

While the state court proceedings were still in progress, HHS, which had received a Section 504 complaint from an unidentified person, referred the matter to the New York state child protective service agency. (Pet. App. 8a).

Secretary has relied on the "Baby Doe of Indiana" case as justification for her regulatory approach, although it involved a decision by parents not to authorize treatment, which the Secretary now concedes is outside the scope of Section 504. *See* 47 Fed. Reg. 26027 (1982) (J.A. 127); 48 Fed. Reg. 9631 (1983); 48 Fed. Reg. 30847 (1983); 49 Fed. Reg. 1623 (1984) (J.A. 14). *See also* 49 Fed. Reg. 1646 (1984) (J.A. 96) (summarizing HHS's formal investigation of case).

[26] The trial court granted this request, but was immediately overruled by the Appellate Division, which determined that the parents' decision was in the best interests of the child. (Pet. App. 7a). The New York Court of Appeals affirmed on October 28, 1983. (Pet. App. 7a-8a).

Without waiting for the state agency to make its determination, HHS in late October began its own direct Section 504 investigation, repeatedly requesting the patient's records. (Pet. App. 8a). University Hospital declined to give Baby Jane Doe's medical records to HHS, based in part on the parents' refusal to release them. On November 2, 1983, *before* the state child protective service agency had reached a decision, HHS and the Department of Justice brought a federal court action under Section 504 seeking access to the records to determine if the parents were making a reasonable medical decision. The government then persisted in its suit even after the state courts had refused to override the parents' choice and after the state agency concluded on November 7, 1983 that no state intervention was warranted under New York's child neglect statute. (Pet. App. 8a-11a).

To protect their interests, Baby Jane Doe's parents were forced to intervene in the federal suit, after defending a state court action and answering a state child protective service agency inquiry. This harassing federal lawsuit, which ignored state administrative and judicial decisions, exposed the parents to continued, unwanted publicity and imposed on them over $75,000 in additional legal fees. *See* 130 Cong. Rec. S8017 (daily ed. June 21, 1984). Given her explicit concession that she has no authority under Section 504 to investigate parents, the Secretary has implicitly conceded that the result in *University Hospital*—barring her investigation of Baby Jane Doe's parents—was correct and her harassing lawsuit was completely unjustified.[27]

C. An Affirmance On This Issue Is Necessary.

Notwithstanding HHS's concession of July 1983 and January 1984 that it is forbidden, under Section 504,

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[27] HHS can hardly argue with any credibility that it was seeking to investigate whether physicians or hospitals were discharging their duties under state law to report parental neglect since the suit was brought while the state agency was considering the issue of parental neglect and continued after the agency determined there was no such neglect.

to investigate or regulate individual treatment decisions of parents, a holding of this Court on this issue is necessary for two related reasons. First, such a holding is required to ensure that the Secretary does not unlawfully continue to investigate parents and thereby to ensure that *University Hospital* will never be repeated. Despite the July 1983 concession in the proposed regulation, 48 Fed. Reg. 30848 (1983), the Secretary nonetheless commenced, in October and November of 1983, the Baby Jane Doe investigation and lawsuit that led to the decision in *University Hospital.* Indeed, following her concession in July 1983, the Secretary launched at least 12 investigations which appear to have been directed solely at parents' decisions not to authorize treatment and which were stopped only when the injunction was entered in this case. (J.A. 103-105; cases No. 38-No. 49).

Second, three of the four mandatory provisions of the Final Regulation are aimed directly at parental decision-making. The notice which hospitals must post under the Final Regulation is unquestionably aimed at parents because it recites that any withholding of medically beneficial care from an impaired newborn violates Section 504, with no suggestion, much less clarification, that Section 504 is wholly inapplicable if such decisions are made, as they must be, by parents. 45 C.F.R. § 84.55(b) (J.A. 112-114).[28] Similarly, the mandatory provisions authorizing expedited HHS access to infant medical records and expedited compliance actions do not clearly exclude treatment decisions by parents from HHS's reach; they broadly establish HHS's authority both to investigate the parents' decisions concerning the course of treatment for their impaired infant child and to institute a federal court action to override the parents' decision, as HHS's own investigations demonstrate. 45 C.F.R. § 84.55(d),

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[28] *See* 49 Fed. Reg. 1625-1626 (1984) (J.A. 23-27) (refusal of HHS to make non-applicability to parents clear in notice, despite concession that Section 504 does not apply to parental decisions).

§ 84.55(e) (J.A. 115-116).[29] Thus, a holding by this Court that Section 504 does not apply to parents' treatment decisions is also necessary to invalidate three of the four mandatory provisions of the Final Resolution.[30]

II. THE SECRETARY HAS NO AUTHORITY TO INVESTIGATE AND DETERMINE, BEFORE STATE OFFICIALS HAVE ACTED, WHETHER PHYSICIANS ARE DISCHARGING THEIR STATE LAW DUTIES TO REPORT MEDICAL NEGLECT BY PARENTS.

Having been forced to admit that she cannot investigate and regulate parents' decisions not to consent to treatment for their infant, the Secretary in the Final Regulation impermissibly asserts her authority to do indirectly what she concedes she cannot do directly—to pressure parents by investigating and determining, before state authorities have acted, whether health care providers are discharging their duties under state law to report parental "medical neglect" to state authorities. This contorted view of Section 504 violates the statute because HHS is investigating neglect of a single child, not discrimination between the handicapped and non-handicapped —an investigation which will necessarily and impermissibly require HHS to determine, before state authorities have acted, whether the level of care requested by parents is adequate under varying state standards of medical care in these complex cases. This application of Section 504 is, to use Justice Powell's phrase, not only an illegal but also an "unedifying example of over-zealousness on the part of the Federal government." *Grove City College* v. *Bell*, 104 S. Ct. 1211, 1223 (1984).

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[29] The expedited access to medical records is designed to enable HHS investigators to review and monitor the treatment of infants, which is the prerogative of parents.

[30] The other mandatory provision of the Final Regulation, 45 C.F.R. § 84.55(c) (J.A. 114-115), relates solely, for purposes of this case, to HHS's authority directly to investigate and regulate health care providers, not parents. *See* pp. 25-27.

A. HHS Has Arrogated To Itself State Law Functions.

As noted, under the statutes of all 50 states, health care providers have a duty to report to state authorities known or suspected instances of medical neglect by parents. Similarly, allegations that health care providers themselves have not discharged their statutory reporting duty are investigated by the state's child protective service agencies or prosecutors. Thus, any health care provider's failure to discharge the state law duty to report known or suspected instances of medical neglect must be adjudicated ultimately in state court—and a violation of that duty can lead to a criminal prosecution and criminal sanctions.[31]

With respect to cases where parents do not consent to treatment, the Secretary in the Final Regulation shifted position and claimed that she may investigate directly and immediately after the birth of a severely impaired child the issue of whether health care providers are discharging their *state law duties* to report parental medical neglect. Section 84.55(c) of the Final Regulation (J.A. 114; emphasis supplied) requires, under "authority pursuant to State law" that "health care providers report on a timely basis *to the state agency* circumstances which they determine to constitute *known or suspected instances of unlawful medical neglect* [by parents] of handicapped

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[31] The child abuse and neglect statutes in all 50 states impose upon physicians, and other health care professionals, a mandatory reporting duty which arises whenever the provider either knows of or suspects, or has reasonable cause to know of or suspect, the occurrence of child abuse and/or neglect. Each statute designates a state welfare and/or law enforcement agency as having responsibility for receiving reports, conducting investigations and initiating appropriate judicial proceedings. The failure of a physician or other health care official to report a suspected instance of abuse or neglect to the requisite agency is punishable in every state by criminal or civil penalties or both. *See* R. Horowitz & H. David., LEGAL RIGHTS OF CHILDREN § 7.12 (1984). *See also e.g.*, CAL. PENAL CODE § 11172(d) (West Supp. 1985); ILL. REV. STAT. ch. 111, § 4433 (Smith-Hurd Supp. 1984-1985); MASS. ANN. LAWS ch. 119, § 51A (Michie/Law. Co-op. Supp. 1985); N.Y. SOC. SERV. LAW § 420 (McKinney 1983).

infants." Similarly, the interpretative guidelines to the Final Regulation state (J.A. 122; emphasis supplied):

> Section 504 . . . [is] not applicable to parents. However, each recipient health care provider must in *all aspects* of its health care programs receiving Federal financial assistance provide health care and related services in a manner consistent with the requirements of Section 504 . . . . *Such aspects includes* [*sic*] *decisions on whether to report, as required by State law . . . , to the appropriate child protective services agency a suspected instance of medical neglect of a child* [by its parents]. . . .

As the preamble states (49 Fed. Reg. 1631; J.A. 44; emphasis supplied):

> [T]he proper analysis of the applicability of section 504 in cases where the failure to provide medically indicated treatment is due to a lack of parental consent is that a recipient hospital *is not required to seek to unilaterally overrule the parents*, but it must adhere to the standard practice, *as required by state law*, to make a report to the state agency . . . .[32]

Although the Secretary uses violations of state reporting duties as the predicate for a finding of discrimination, she does not leave the determination of whether physicians have discharged their reporting duties under state law to the duly constituted state executive and judicial authorities. Rather, the Secretary asserts her authority, under Section 504, to make an independent investigation and determination even before state authorities have acted.[33] Implicit in this determination is the issue of whether the child is receiving medicaliy indi-

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[32] The proposition that the physicians' reporting duty is based on state law is repeated throughout the preamble to the Final Regulation. 49 Fed. Reg. 1624, 1627, 1631, 1644 (J.A. 19, 27-28, 44, 90). *See also* 48 Fed. Reg. 30848-30849 (1983); Pet. 6; HHS Br. 7, 27.

[33] 49 Fed. Reg. 1632 (1984) (J.A. 47-48). Section 84.55(d), as noted, provides for "expedited access" to records, including access at any hour of the day or night. (J.A. 115). Section 84.55(e) provides for "expedited action to effect compliance," and HHS claims authority to do this without providing notice to the hospital or physician. (J.A. 115-116).

cated treatment under state law standards. Only if a child's parents do not appear to be authorizing adequate care is there a basis for a physician to report the parents to state authorities for possible neglect. Incredibly, the Secretary thus claims the power in a federal administrative proceeding to make a determination of the adequacy of treatment under state law standards of medical care in these complex cases (standards which may vary from state to state) in order to see if physicians' reporting duties have been violated. Thus, the Secretary claims that HHS, a federal agency with no power to enforce any state's law, can *immediately* determine when there has been a "failure [by a provider] to comply" with varying *state law reporting requirements* in each of the 50 states and can seek a temporary restraining order to stop such *state* law violations. 49 Fed. Reg. 1628 (1984) (J.A. 33).

B. HHS's Arrogation Of State Law Functions To Itself Does Violence To The Language Of Section 504.

The Secretary's claimed ability to substitute her "Baby Doe squads" for state child protective agencies, state prosecutors and even state courts in determining whether health care providers have violated state law reporting duties is demonstrably not authorized by the language of Section 504. The Secretary's brief makes virtually no attempt to show that her claimed authority is supported by the words of the statute—and no such showing is possible. HHS Br. 27.

1. *"Otherwise Qualified" And "Subjected To Discrimination."* In *Alexander* v. *Choate*, 105 S. Ct. 712, 720 n.19 (1985), this Court stated that the "question of who is 'otherwise qualified' and what actions constitute 'discrimination' under" Section 504 "would seem to be two sides of a single coin." When parents of a severely impaired child do not consent to medical treatment in a federally funded health program, the child is not "otherwise qualified" for such treatment within the terms of Section 504. In such circumstances, recipients of federal health care funds do not fail to provide treatment in a federally funded health program solely on the basis of the child's

handicap, but rather solely on the basis of the child's infancy.[34] The Secretary does not—and cannot—dispute this unassailable conclusion which removes federally funded hospitals from the reach of Section 504 when parents do not consent to treatment on behalf of their child. HHS Br. 21-26.

Instead, in an improper attempt to bring federally funded hospitals within the reach of Section 504 in a situation involving potential parental *neglect* of a single child—not *discrimination* between an impaired child and a non-impaired child regarding access to a federally funded health program—the Secretary simply asserts without citation that, under the "subjected to discrimination" language of Section 504, health care providers may not fail to discharge their state law duties to report the parents of severely impaired children to state law authorities. HHS Br. 27. But only when there has been such a final state law determination of a physician's reporting violation, which would involve complex medical and legal considerations in individual cases under the varying laws of each state, could HHS even conceivably begin to determine whether the violation constituted "discrimination" against the severely impaired child within the meaning of Section 504.

It must be emphasized that, in making such a determination, HHS would necessarily and impermissibly have

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[34] In *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979), this Court stated that the plain meaning of "otherwise qualified handicapped individual" is "one who is able to meet all of a program's requirements in spite of his handicap." When parents do not provide consent to treatment for a severely impaired child, one of the requirements of a health care program—consent to treatment—is not present and thus the severely impaired child is not "otherwise qualified" for treatment in that program.

Nor does HHS even attempt to show that an impaired newborn is "otherwise qualified" to have a recipient of federal funds in a *health care program* provide access, not to that federally funded health care program, but instead to state administrative and judicial processes for determination under state law standards of the parents' fitness to make medical decisions on the infants' behalf when its parents have not consented to treatment.

to determine the adequacy of the care a child was receiving under the varying standards of medical care in the 50 states because only if the care requested by parents is, or appears to be, inadequate are physicians required under state law to report parents for possible neglect. *See* note 31, *supra*. In its brief, HHS never addresses this obvious and fatal implication of its regulatory approach—which is built on the distinction between *bona fide* and discriminatory care in individual cases (HHS Br. 16)—and thus never attempts to respond to the basic holding of the Court of Appeals in *University Hospital* that determinations by HHS of the standard of medical care in individual cases is simply not authorized by Section 504. HHS Br. 26-38.[35] Thus, the express language of Section 504 demonstrably does not authorize the Secretary to make an independent federal investigation and determination of whether recipients of federal health care funds have violated state child abuse and neglect laws—including the necessary determination of whether a child has received appropriate medical care under state law standards—*before* a final state court judgment to that effect.[36] *See* pp. 25-27, *supra*.[37]

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[35] Neither the language, nor the legislative history, *see* pp. 42-45, *infra*, of Section 504 authorizes such an unprecedented expansion of federal power, as the Court of Appeals correctly held. *See* Pet. App. 30a-31a ("subjected to discrimination" language of Section 504 does not authorize HHS to establish standard of medical care for distinguishing *bona fide* medical judgments from discriminatory ones).

Respondents AMA *et al.* do not maintain, by this discussion, that a violation of a state reporting duty, as determined by a final state court judgment, would give rise to a Section 504 violation. That issue is not before this Court. Our position is only that no Section 504 action is even conceivable without such a final judgment.

[36] The issue of whether, and to what extent, the Secretary can investigate and regulate the enforcement practices of state child protective service agencies which receive federal child abuse funds—as opposed to the state law reporting duties of health care providers who receive federal health care funds—is not presented in this case.

[37] There are occasional HHS statements that "discriminatory" applications of hospitals' "policies" and "practices" of either report-

2. *"Program Or Activity Receiving Federal Financial Assistance"*. This Court has made clear that simply because an entity, including a hospital, receives federal money does not mean that every action taken by that entity is subject to the federal antidiscrimination ban under Title VI, Title IX or Section 504. Instead, the phrase "program or activity" is a limiting concept and the duties created by those statutes are program-specific in their reach. *Consolidated Rail Corp.* v. *Darrone*, 104 S. Ct. 1248, 1255-1256 (1984); *Grove City College* v. *Bell*, 104 S. Ct. 1211, 1220-1222 (1984); *North Haven Board of Education* v. *Bell*, 456 U.S. 512, 538 (1982).

In support of her claimed authority to regulate physicians' state law reporting duties, the Secretary simply asserts in a single sentence, without citation, that the physicians' duty, established under state statute, to report parental medical neglect to state authorities is part of a federally funded "program or activity." HHS Br. 27. But this assertion is certainly not supported by the plain meaning of Section 504. It is, to the contrary, a very contorted use of the term "program," in the context of the provision of health care, to apply it to a physician's decision required solely by state law to report parents of infant children to state authorities for enforcement of the state's neglect statute. Indeed, in its brief, HHS concedes that the Final Regulation has made no showing that these state law reporting duties are part of a federally funded program or activity. HHS Br. 21 n.9. As a matter of

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ing parental neglect or seeking court orders displacing parents as decisionmakers may violate Section 504. 49 Fed. Reg. 1631 (J.A. 43); HHS Br. 27. The short answer to that erroneous contention is that the Final Regulation itself is clearly restricted to enforcing the *state law* duties of hospitals and physicians. *See* 45 C.F.R. § 84.55(c) (J.A. 114-115) and pp. 25-27, *supra*. Moreover, since such "practices" in fact involve nothing more than the hospital's efforts to comply with state law (in the case of reporting "neglect") or to make state law judgments (in the case of taking "neglectful" parents to court), HHS's investigations of such "practices" would necessarily, and improperly, require HHS to make state law judgments *based in part on its own view of state standards of medical care in individual cases.*

law, at least a *minimal* showing by HHS that the activity being regulated is part of a federally funded "program or activity" should be required before such intrusive regulations are allowed.[38]

C. HHS's Arrogation Of State Law Functions To Itself Is Not Authorized By The Legislative History Of Section 504.

The legislative history of Section 504 also does not authorize the Secretary to make an independent investigation and determination whether a health care provider who is the recipient of federal health care funds is violating reporting duties established by state child neglect statutes before state executive and judicial officials have acted. HHS's 15-page discussion in its brief (pp. 29-44) of the legislative history of Section 504 adduces *no* authority from the congressional deliberations to support its contorted position that it has authority to make state law judgments before state authorities do.[39]

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[38] The legal requirement that a regulation must have a factual basis to justify the burdens it imposes is derived from both the Administrative Procedure Act, 5 U.S.C. §§ 551 *et seq.*, and Section 504. The APA requires every agency rule to be supported, at a minimum, by a reasonable basis in fact. *See* page 40, *infra*. In addition, it would be fundamentally inconsistent with the limitations in the scope of Section 504, recognized by this Court in *Alexander* v. *Choate*, 105 S. Ct. 712 (1985) (page 32, *infra*), to allow an agency to delve into a new area of enforcement, never contemplated by Congress, without making at least a minimal showing that the decisions being regulated are related to some federally funded activity. But as noted above, the Secretary has conceded that she has made no such showing with respect to physicians' state reporting duties. HHS Br. 21 n.9.

[39] During the course of its discussion of the legislative history, HHS also discusses the general Section 504 regulation which was promulgated in 1977 to implement the legislation and which was subsequently cited in the 1978 amendments to Section 504. HHS Br. 39-44. Again, HHS cites *nothing* in that general regulation which authorizes HHS to investigate and determine violations of state law reporting duties before state officials have acted. *See also* pp. 42-45, *infra* (legislative history of Section 504 provides no authority for HHS to apply *state* standards of adequate medical care to individual cases or to establish *federal* standards of medical care for evaluating such cases).

D. HHS's Arrogation Of State Law Functions To Itself Violates Basic Canons Of Section 504 Construction.

Although the Secretary's attempt to make state law judgments before state officials have acted is clearly not authorized by the language and legislative history of Section 504, any ambiguity on the reach of the statutory language clearly must be resolved against the Secretary. This Court has held that the determination of the scope of Section 504 must be responsive to two powerful but countervailing considerations—the need to give effect to the statutory objectives of protecting the beneficiaries of the Act and the desire to keep Section 504 within manageable bounds. *Alexander, supra*, 105 S. Ct. at 720. This Court in *Alexander* thus restated the fundamental rule of Section 504 construction set forth in *Southeastern Community College* v. *Davis, supra* (105 S. Ct. at 720; emphasis supplied):

> *Davis* thus struck a *balance* between the statutory rights of the handicapped to be integrated into society and the legitimate interests of federal grantees in preserving the integrity of their programs: *while a grantee need not be required to make "fundamental" or "substantial" modifications to accommodate the handicapped, it may be required to make "reasonable" ones.*

Thus, in contrast to other civil rights statutes, such as Title VI, Section 504 requires the judiciary to make an independent inquiry into the reasonableness of HHS action when it is not clearly authorized by the Congress.[40]

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[40] Unlike race, which never is a *bona fide* consideration underlying any particular decision unless used to remedy the effects of past discrimination, handicap may be a relevant factor in deciding whether someone is qualified for access to federally funded programs. For this reason Section 504 cannot be and has not been interpreted by this Court in the same way as a statute such as Title VI, even though Section 504 was in broad outline patterned after Title VI. *See Alexander* v. *Choate*; Note, *Employment Discrimination Against The Handicapped and Section 504 of the Rehabilitation Act: An Essay On Legal Evasiveness*, 97 HARV. L. REV. 997, 1006-1007 (1984). Instead, in a case such as this, the Court must decide whether the accommodation HHS has required health care providers

1. But HHS cannot satisfy the basic rule of construction established in *Alexander*. Its efforts to investigate and regulate directly physicians' state law reporting duties constitute a forbidden "substantial modification" of the providers' health program (even assuming, as we do not, that a federally funded hospital's state law reporting duties are part of any federally funded "program or activity," *see* pp. 30-31, *supra*). Before HHS's regulatory efforts in this area, hospitals and physicians had to respond to investigations by state agents of state law reporting duties and defend court actions brought for failure to discharge such duties. Now, however, the Secretary claims that health care providers also must submit to independent, duplicative and wholly improper state-law-based investigations by HHS in the hours and days after the birth of a severely impaired newborn. Before state authorities have acted, physicians must also defend themselves in an HHS fund withdrawal proceeding which must be bottomed, implausibly, on HHS's determination of whether state law reporting duties have been violated—a determination which necessarily requires HHS in a *federal* forum to show that state standards of reasonable medical care have not been followed and which would necessarily force hospitals and physicians to rebut that showing in these unprecedented "504 malpractice" cases. This is demonstrably a "substantial" modification in the practices of hospitals and physicians because it involves the imposition of a "wholly unwieldy administrative and adjudicative burden" forbidden by *Alexander*. 105 S. Ct. at 719.

Moreover, HHS requires interviews by federal "Baby Doe" squads with physicians, nurses and other professionals; it requires making records available to federal investigators. It thereby has the potential for duplicating any investigation by the state authorities who are duly constituted under state statute to determine whether state reporting laws are being followed. It is hard to imagine

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to make to protect handicapped infants is a reasonable one. *Alexander, supra*, 105 S. Ct. at 720.

a more "substantial" or "fundamental" modification in a program of health care for newborns—a modification which is *not* necessary because HHS simply cannot make state law judgments before state authorities do. Moreover, not only is this a substantial modification, but it is also one which actually causes harm as the uncontradicted record below demonstrates. *American Academy of Pediatrics, supra*, 561 F. Supp. at 396, 399-400 (HHS approach causes "profound change" in way care provided).[41]

2. In *Alexander* v. *Choate*, this Court also stated that the Secretary will have "substantial leeway to explore areas in which discrimination against the handicapped posed *particularly significant problems* and to devise regulations to prohibit such discrimination." 105 S. Ct. at 722 n.24 (emphasis supplied). But despite her attempt to find in that sentence a roving commission to take any action she deems appropriate, HHS Br. 29, 36, it, in fact, offers another reason, if one is needed, to strike down the Secretary's efforts in this area. In *Alexander*, the Court was referring to "particularly significant problems" which had been identified in the general Section 504 regulation promulgated in 1977 by HEW (the predecessor department for these purposes to HHS) and recognized by the Congress in 1978 amendments to Section 504. 105 S. Ct. at 724 n.27. But, there was simply no discussion in those regulations of what HHS itself has conceded are the unique and complex issues surrounding treatment for severely impaired newborns,[42] let alone any mention of the

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[41] *See* p. 12, *supra*. Indeed, even HHS's cursory description of its own reported investigations makes clear that they have resulted in invasions of family privacy, medical records and confidential medical decisionmaking, and have disrupted hospital operations and delayed ongoing treatment for impaired newborns and other patients. (J.A. 95-106). *See also* Shapiro & Rosenberg, *The Effects of Federal Regulations Regarding Handicapped Newborns: A Case Report*, 252 J.A.M.A. 2031 (1984); Strain, *The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 NEW ENG. J. MED. 443 (1983); J.A. 162-186 (unrebutted affidavits submitted in this case).

[42] *See* 49 Fed. Reg. 1636 (1984) (J.A. 61) (noting that application of Section 504 in this area is "much more subtle and difficult" than

need for HHS independently to make state law judgments regarding reporting duties of providers under state child abuse and neglect laws before state officials have acted.

Moreover, the Department has itself failed in the administrative record to demonstrate that there is any problem—let alone a particularly significant one—with providers' failure to discharge such reporting duties *and* with state agencies' failure to enforce those duties. In the 1984 Child Abuse Amendments—the only instance in which the Congress has addressed the question of appropriate care for impaired infants—the Congress sought to strengthen the authority of state agencies, not supplement or supplant it with a duplicative federal role as proposed by the Secretary. *See* pp. 47-48, *infra*; HHS Br. 28, 45. Moreover, in the regulations implementing the 1984 Child Abuse Amendments, the Secretary noted that "only a very small fraction of births involve any serious question of survival" and only "a fraction" of this tiny fraction would "involve even a potential allegation of [parental] medical neglect" under state law. 50 Fed. Reg. 14886-14887 (1985). In fact, the Secretary further conceded in the 1984 Child Abuse Regulation that use of infant care review committees should reduce the already minuscule need for formal *state* legal proceedings against parents involving impaired newborns to a "[v]ery few cases." *Id.* It follows, *a fortiori*, that the problem of health care providers failing to *report* parental neglect is even smaller, and the problem of state agencies failing to deal with such cases is virtually non-existent. *See also* HHS Br. 2-11, 28 (*no* mention of any problem).[43] Accordingly, no

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other areas); *id.* 1632 (J.A. 45-46) (few "definitive statements" on application of Section 504 in this area possible); *id.* 1654 (J.A. 123) ("special circumstances" of each case).

[43] HHS Br. 6 (federal "enforcement" is "unnecessary" given infant care review committees). Nothing in the Final Regulation demonstrates any reporting problem of federal dimensions. The single case noted by HHS did not, by HHS's own account, involve determination of a state law or Section 504 violation, but only the voluntary resolution of a complaint when a hospital stated it would do what it was obligated to do anyway: follow state law. HHS Br. 44; 48 Fed.

deference is due to the Secretary's attempt to regulate a non-existent problem and, therefore, her construction of Section 504 in this regard should be rejected. *See also Skidmore* v. *Swift & Co.*, 323 U.S. 134, 140 (1944); *General Electric Co.* v. *Gilbert*, 429 U.S. 125, 143 (1976) (inconsistent agency interpretation owed no deference).[44]

E. HHS's Arrogation Of State Law Functions To Itself Violates Sound Principles Of Federalism.

The Secretary's assertion of authority to disregard traditional state processes for responding to suspected medical neglect and to investigate and regulate directly health care providers' conduct before the state acts evidences a striking lack of respect for the states and violates another fundamental rule of construction which requires a clear statement of congressional intent. The Secretary makes no effort in either the administrative record or her brief to explain why, given her reliance on state law as the basis for judging physicians' conduct, she is completely unwilling to defer to the states to make state law judgments. This disrespect for the states stands in stark contrast to how the Congress itself ordinarily treats concurrent federal and state enforcement efforts. For instance, in both

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Reg. 30847 (1983). The other cases and studies cited in the Final Regulation do not even address the only relevant question of whether there is some problem with the state child protective service agencies which justifies HHS investigations, not of those agencies themselves, but of the health care professionals regulated by those agencies before those agencies have acted. *See* 49 Fed. Reg. 1645 (1984) (J.A. 90-93).

[44] With respect to situations where parents refuse to consent to treatment, HHS has shifted position dramatically in a short period of time. First, it said physicians should discharge patients from hospitals; then it indicated in its Interim Rule and argued to Judge Gesell that physicians should simply provide treatment against the parents' wishes; and, only when it finally realized that parents have ultimate legal responsibility for their children absent a neglect finding, did it focus on physicians' state law reporting duties. *See* pp. 7-11, *supra*; 49 Fed. Reg. 1631 (1984) (J.A. 43-44). *See also American Academy of Pediatrics, supra*, 561 F. Supp. at 400 (Interim Rule product of "haste and inexperience").

Title VII, 42 U.S.C. § 2000e-5(d), and the Age Discrimination in Employment Act, 29 U.S.C. § 633(b), Congress expressly required federal agencies to refer all discrimination claims in the first instance to a state agency if the state has a parallel anti-discrimination statute. *See Oscar Mayer & Co.* v. *Evans*, 441 U.S. 750, 756 (1979). It is completely incongruous to think that the same Congress intended to authorize HHS in the guise of a federal civil rights statute for the handicapped to enforce physicians' state law reporting duties within hours and days after birth without any deference to the investigations and determinations of state agencies and courts.

Indeed, the Secretary's proposed effort to modify the "federal-state balance" by intruding into the states' traditional regulation of medical neglect cases could only be justified by a clear statement of congressional intent to permit this regulation. *See FTC* v. *Bunte Brothers, Inc.*, 312 U.S. 349, 354-355 (1941); *Apex Hosiery Co.* v. *Leader*, 310 U.S. 469, 513 (1940); *United States* v. *Bass*, 404 U.S. 336 (1971). *Cf., Pennhurst State School & Hospital* v. *Halderman*, 451 U.S. 1, 17 (1981).[45] This Court, in reviewing federal attempts to regulate behavior *concurrently* with the states, has held that, absent a "clear statement" of congressional intent, the federal action was prohibited. That rule applies with special force in this case. Here the Secretary is acting in an area historically ceded to the states: the regulation of sensitive parent-child and physician-patient relationships, under the states' *parens patriae* and police powers. *See* pp. 3-4, *supra*. Thus, this case is even more extreme than other "concurrent regulation" cases requiring a clear statement of Congressional intent because the duties of the health care providers to report parental neglect which the Secretary seeks to regulate arise *solely* under state law. Absent a clear statement from the Congress, the Secretary simply may not precede, duplicate and/or supplant state execu-

[45] *See, e.g., Williams* v. *United States*, 458 U.S. 279, 290 (1982); *United States* v. *Enmons*, 410 U.S. 396, 411 (1973); *Palmer* v. *Massachusetts*, 308 U.S. 79, 83-85 (1939).

tive and judicial authorities who investigate and determine whether state law reporting duties have been violated by health care professionals.[46]

III. THE SECRETARY HAS NO AUTHORITY TO INVESTIGATE AND REGULATE PHYSICIANS' TREATMENT DECISIONS IN INDIVIDUAL CASES.

In addition to her unlawful application of Section 504 to providers' duties under state law to report for neglect parents who do not authorize treatment, the Secretary has also claimed authority to apply the statute to decisions by providers not to treat impaired newborns. HHS Br. 13. Such provider decisions not to treat can arise in only two circumstances: when parents have not consented to treatment for their child and when they have. In neither circumstance is action by the Secretary lawful.

A. Providers' Decisions Not To Treat In Cases Where Parents Have Withheld Consent To Treatment.

In the preamble to the Final Regulation, HHS finally conceded that health care providers have no authority to treat an infant over parents' objections and that, as a result, providers' treatment decisions in these circumstances are wholly beyond the purview of Section 504. *See, e.g.*, J.A. 43-44; HHS Br. 27-28. Nevertheless, because HHS has in previous statements—most notably in the Interim Rule, 48 Fed. Reg. 9630 (1983)—asserted authority under Section 504 to require providers to treat infants over their parents' objections, and has ignored other concessions in prosecuting *University Hospital*, it is appropriate that this Court formally hold that Section 504 does not apply to providers' treatment decisions when the parents have withheld consent to treatment.

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[46] HHS's efforts to enforce parental neglect reporting duties are also invalid under the fundamental rule of construction that a government agency or department cannot do indirectly what it is prohibited from doing directly (*i.e.*, regulate parents' decisions). *See T.I.M.E., Inc.* v. *United States*, 359 U.S. 464 (1959). *See also Montana-Dakota Utilities Co.* v. *Northwestern Public Service Co.*, 341 U.S. 246 (1951); *Sunray Mid-Continent Oil Co.* v. *FPC*, 364 U.S. 137, 152 (1960).

B. Providers' Decisions Not To Treat In Cases Where Parents Have Authorized Treatment.

In this Court, HHS devotes virtually all of its brief to the argument that it is authorized under Section 504 to investigate and regulate directly providers' decisions not to provide treatment when parents have given their consent. But this Court need not even reach this issue of construction because the application of Section 504 to such decisions is clearly unlawful under the Administrative Procedure Act ("APA"). 5 U.S.C. § 551 *et seq.*[47] In any event, this application of the Regulation is also not authorized by Section 504.

1. *The Application Of The Final Regulation To Such Decisions Is Arbitrary And Capricious.*

Because the application of Section 504 to provider decisions not to treat in individual cases invades an area traditionally governed by state law processes, the Secretary may regulate them, if at all, only on the basis of a valid, *specific* regulation. Under *Alexander* v. *Choate*, she cannot rely solely on any inherent Section 504 authority under the statute or the general implementing regulations.[48] But, the Final Regulation cannot provide her such specific authority because application of that regu-

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[47] *See* J.A. 146-147 (respondents AMA *et al.* alleged APA count in their complaint) and note 19, *supra* (this Court may affirm judgment on alternate ground).

[48] In *Alexander*, this Court held that the Secretary could not, simply on the authority of the "generally-worded" Section 504 regulations promulgated in 1977, intrude on the states' traditional discretion in administering Medicaid, a federal/state program, if such action was not explicitly authorized by the statute, its legislative history or the general regulation. 105 S. Ct. at 724 & n.32. The need for a specific implementing regulation before the Secretary may act is even stronger with respect to physicians' treatment decisions where the application of Section 504 is wholly unprecedented, intrudes on existing state law standards governing the reasonableness of medical practice in individual cases, and is not explicitly authorized. *Cf.*, 42 U.S.C. § 1395 (disavowing federal supervision or control over the practice of medicine).

lation to these provider treatment decisions violates elementary principles of administrative law.

Under the APA, courts must invalidate regulations that are "arbitrary, capricious, [or] an abuse of discretion." 5 U.S.C. § 706(2)(A). This Court has consistently interpreted this provision to require, at a minimum, that administrative rules have a reasonable basis *in fact* and that the agency or department articulate a satisfactory explanation for its action, including a "rational connection between the facts found and the choice made." *See Motor Vehicle Manufacturers Assoc. of the United States, Inc.* v. *State Farm Mutual Automobile Insurance Co.*, 463 U.S. 29, 43 (1983).[49] The Secretary's claim in her brief that, under the Final Regulation, she may investigate and regulate directly providers' decisions not to treat after parents consent fails to withstand scrutiny under both of these basic requirements.

First, and most importantly, the Secretary's argument is totally unsupported by any factual evidence that such alleged decisions are ever made by health care providers in the context of care for impaired newborns. Indeed, this "case" involves a wholly hypothetical situation that is on its face implausible: a health care provider would first have to communicate the treatment options to the infant's parents and then, after the parents selected a course of treatment, fail to provide it solely because of the infant's handicap. Such a failure to treat could subject the physician to tort liability and state disciplinary action under the licensing laws of all 50 states. *See* pp. 4-5, *supra*. Of course, HHS has not been able to cite even a single instance in which a provider has refused to provide a newborn infant medically indicated treatment which its parents have authorized—not in the preamble to the Final Regulation, not in any of her

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[49] This fundamental rule has often been emphasized by the Court. *See, e.g., Bowman Transportation, Inc.* v. *Arkansas-Best Freight System, Inc.*, 419 U.S. 281, 285-86 (1974); *Citizens to Preserve Overton Park, Inc.* v. *Volpe*, 401 U.S. 402, 416 (1971); *Burlington Truck Lines, Inc.* v. *United States*, 371 U.S. 156, 168 (1962).

lengthy regulatory pronouncements in this area, and not in her brief to this Court, which remarkably contains not one citation to *any* authority suggesting even the existence of such a case.[50]

Second, given its failure to cite a single case of what it purports to be regulating, HHS has *a fortiori* not been able in the preamble to the Final Regulation to establish any connection, much less a "rational connection," between the administrative record and its claimed authority to investigate providers' decisions in these circumstances. Indeed, there does not appear to be a single word in the Final Regulation, in its preamble, or in any of HHS's regulatory pronouncements even remotely suggesting that the purpose of HHS's presence in the delivery rooms and newborn nurseries was to review alleged provider decisions not to treat when parents of impaired newborns have authorized treatment.[51] In short, one looks in vain in the Secretary's regulatory pronouncements for any mention of, or justification for, the application of the Final Regulation to the hypothetical provider "non-treatment" decisions which are virtually the sole focus of her brief in this Court. The application of the Final Regulation to such decisions is demonstrably arbitrary and capricious and, therefore, unlawful, and this Court should so hold to prevent HHS from using it as a pretext to conduct intrusive, harmful investigations.[52]

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[50] *See* HHS Br. 15, 26 (HHS's paradigm example of refusal to treat is hypothetical only; no citation to specific case). *See also* 49 Fed. Reg. 1646-1649 (1984) (J.A. 95-106) (none of 49 cases reported by HHS involved this situation). In *University Hospital*, for example, the Court of Appeals noted that the hospital remained willing to perform corrective surgery on Baby Jane Doe if her parents would consent. (Pet. App. 39a). In the Baby Doe of Indiana case, parents refused to authorize treatment. HHS Br. 2.

[51] Moreover, nowhere in the administrative record did the Secretary ever discuss the state law duties of health care providers under state licensing statutes not to "abandon" patients; and nowhere did she explain why existing state law processes need to be short-circuited by her own direct involvement in the first instance.

[52] Moreover, the Secretary cannot, in her reply brief to this Court, make up for these obvious deficiencies. Administrative action may

2. *Section 504 Does Not Authorize Direct Federal Investigation And Regulation Of Such Provider Treatment Decisions.*

Application of the Final Regulation to physicians' decisions not to treat when parents have consented is also unlawful because it is plainly outside the scope of the Secretary's authority under Section 504.

a. The vast bulk of the Secretary's brief is spent deriving two propositions from the language and legislative history of Section 504. But neither proposition supports the Secretary's authority to investigate and determine the "reasonableness" of physicians' decisions in individual cases. First, HHS maintains that Section 504 applies generally to health services and mandates nondiscriminatory access to federally funded health services for otherwise qualified handicapped individuals.[53] This proposition, of course, is nothing more than a restatement of the general rule of Section 504 itself, and there have been a number of cases decided by the lower federal courts involving Section 504 and health services—none of which remotely supports the extreme construction of the statute urged here by the Secretary.[54]

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be upheld by a reviewing court, if at all, only on the same grounds articulated by the agency itself, and "appellate counsel's *post hoc* rationalizations for agency action" are impermissible. *Burlington Truck Lines, supra*, 371 U.S. at 168-169.

[53] The Secretary places principal reliance on the Senate report accompanying the 1974 amendment to Section 504 which listed "health services" along with employment, housing, transportation and education as areas to which Section 504 would apply. HHS Br. 35; S. Rep. No. 1297, 93rd Cong., 2d Sess. 39 (1974). *But cf., Alexander, supra*, 105 S. Ct. at 724 (the principal focus of Section 504 was not on health services but rather on employment, education and the elimination of physical barriers).

[54] *See, e.g., United States* v. *Cabrini Medical Center*, 639 F.2d 908 (2d Cir. 1981) (employment); *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979) (admission to nursing school); *Alexander* v. *Choate*, 105 S. Ct. 712 (1985) (reduction in health assistance). No case has approved the application of Section 504 to individual medical treatment decisions. Indeed, the Eighth

Second, HHS maintains that Section 504 specifically applies to "treatment" decisions involving otherwise qualified handicapped individuals. Although its brief is filled with enumerable references to bills, amendments and reports, HHS derives this proposition not from the legislative history of Section 504 but only from several examples —involving denial of medical treatment due to race, deafness, alcoholism and drug addiction—contained in the legislative histories of other statutes or in the preamble of the general Section 504 regulation promulgated in 1977.[55] But these examples, on their face, do not involve a federal determination first of an appropriate standard of medical care in an individual case and then a determination that the health care provider did not act in a "reasonable" or "*bona fide*" medical fashion. Instead, these examples all involve discriminatory general policies declaring *ineligible* for treatment broad types of individuals in which the minority status or handicapping condition—blacks denied surgery, deaf persons denied burn treatment and alcoholics denied cancer therapy—is on its face wholly unrelated to the condition requiring treatment.

Circuit recently dismissed a Section 504 claim alleging, in part, that a nursing home had discriminated against a resident by failing to provide adequate medical care, concluding that "[i]n substance, this is a medical malpractice case" not cognizable under Section 504. *Hoyt* v. *St. Mary's Rehabilitation Center*, 711 F.2d 864, 867 (8th Cir. 1983).

[55] *See* HHS Br. 11, 35-36 (example, drawn from Title VI, of black person denied medical treatment); *id.* 40 (example, drawn from 1977 general Section 504 regulations, of deaf person denied care by a burn treatment center); *id.* 37-39, 41-42 (example, drawn from 42 U.S.C. § 290dd-2(a), of alcoholic or drug addict denied care for unrelated medical condition). The only "health services" example drawn from the legislative history of Section 504 itself has nothing to do with treatment in individual cases after admission to a program. The Senate Report cites as the *only* example of the application of Section 504 to health services the denial of *admission* to a federally assisted nursing home solely on the basis of handicap. S. Rep. No. 1297, *supra*, at 38-39.

These examples are in sharp contrast to the Secretary's claim in this Court regarding her authority to investigate physicians' decisions involving impaired infants. The Secretary concedes that application of Section 504 to medical treatment decisions involving severely ill infants is "much more subtle and difficult" than more conventional applications, 49 Fed. Reg. 1636 (1984) (J.A. 61), and that, because of the inherent difficulty and complexity of determining appropriate medical care for impaired newborns, she is simply unable to develop even the most general standards for applying Section 504 in this swiftly changing area of medical practice, 49 Fed. Reg. 1632 (1984) (J.A. 46). Thus, the Secretary has announced that she can and will proceed only on a "case-by-case basis" to assess the standard of reasonable care with respect to the complex cases and then to determine whether providers in individual cases have made "reasonable" or *bona fide* medical treatment decisions as opposed to discriminatory decisions based solely on the handicap of an otherwise qualified infant. 49 Fed. Reg. 1632 (1984) (J.A. 46). *But cf., id.* 1634 (J.A. 52) (HHS refusal to commit to use medical consultants in all on-site investigations).

At the very least, as the Court of Appeals in *University Hospital* noted, the determination of whether a provider has "discriminated" in this sense against his infant patient would necessarily involve federally established "504 malpractice" standards, lengthy litigation, extraordinarily burdensome administrative costs, and no sure conclusion, especially in the highly complex and swiftly changing field of neonatology. (Pet. App. 30a-31a). As the only courts to address this issue have concluded, there is simply no support anywhere in the legislative history for this kind of direct establishment by HHS of a federal standard of care in individual cases and then a further determination whether providers have deviated from that standard of care in a way that is "discriminatory"

under Section 504.[56] Congress simply did not intend that HHS would determine in individual cases whether or not "medical treatment [was] contraindicated." HHS Br. 24.

b. The total lack of support in the "subjected to discrimination" language of Section 504 and in the legislative history of the Act for the Secretary's attempt to investigate and regulate directly the "reasonableness" of a physician's decision not to treat in an individual case after parental consent has been given should end the inquiry. But, even if there is some ambiguity on this point in the legislative history, the Secretary is barred from such an application of Section 504 because it would require a "substantial modification" in the provider's program prohibited under the rule of *Alexander* v. *Choate*.

If parents have consented to treatment, HHS can investigate only two types of situations. In the first, the physician does not himself treat but responds to the infant's condition by helping to obtain an alternative physician satisfactory to the parents.[57] In that situation the infant receives treatment, but HHS could nevertheless make a federal "504 malpractice" investigation and de-

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[56] *See University Hospital, supra*, 729 F.2d at 157-160 (Pet. App. 31a-38a); *American Academy of Pediatrics, supra*, 561 F. Supp. at 400 ("there is no customary standard of care" of impaired infants), 401 ("no congressional committee or member of the House or Senate ever even suggested that Section 504 would be used to monitor medical treatment of defective newborn infants . . ."). As noted, in its brief, HHS never addresses this fundamental holding in the Court of Appeals opinion. HHS Br. 26-28. *See* 49 Fed. Reg. 1630 (1984) (J.A. 38-39) (HHS recognition that individual cases will turn on experience and judgment). The hypothetical case cited repeatedly by HHS—a Down's Syndrome infant who is denied surgery to correct a blocked esophagus (HHS Br. 12-13, 15, 23, 26)—is, as HHS's *own emphasis* on case-by-case determinations indicates, a simplified example which is not likely to reflect medical realities. *See* pp. 5-7, *supra*; Brief for *Amici Curiae* American Academy of Pediatrics, *et al.* *See also* HHS Br. 5 n.2 (recognition of complicating factors).

[57] This could happen if the physician were faced with two emergencies simultaneously and could only treat one.

termination, even though no unlawful "abandonment" under state law has occurred. *See* p. 4, *supra*. The new federal substantive standard of medical care imposed upon health care providers in such a circumstance would involve an even more "fundamental modification" of a hospital's treatment program than the Secretary's attempt to enforce existing state reporting duties because federal standards of medical care are being established and enforced. Any HHS efforts to devise and enforce federal medical standards of care in this type of situation, where there has been no patient abandonment under state law, plainly violates the rule in *Alexander* v. *Choate*.

In the second situation, which is wholly implausible, the physician, after receiving parental consent, both refuses to treat a child who is severely impaired and declines in clear violation of state law to help parents secure a second physician to treat the infant. Obviously, this would be scandalous, but even in this hypothetical circumstance all of the rules of construction discussed in Part II undercut HHS's attempt to regulate before state authorities have acted. The federal intrusion laid on top of existing state enforcement mechanisms to deal with patient "abandonment" will significantly modify the hospital's program. *No* problem has been identified by the Secretary that warrants a federal role and therefore no deference is due to her extreme construction of the Act. Finally, the state would surely prosecute such a case and its prerogatives should not be interfered with solely on the basis of a tortured reading of Section 504 and without a clear statement from Congress that it wanted HHS involved in this fundamental issue of state regulation of medical practice.[58] Under applicable rules

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[58] There is little danger that, if such a scandalous case ever occurred, state authorities would not proceed promptly against the physician and any federal interest could be vindicated, as appropriate, after a final state law determination. There is danger, however, that if HHS is allowed to investigate this "type" of case before final state action it will, as it has in the past, direct its attention to cases where parents have not consented to treatment.

of construction, HHS simply cannot bootstrap itself into intensive care nurseries with broad Section 504 investigative powers based on so flimsy a hypothetical.

CONCLUSION

In *University Hospital*, the Court of Appeals concluded by noting (Pet. App. 40a-41a) that:

> it is congress, rather than an executive agency, that must weigh the competing interests at stake in this context in the first instance. Until congress has spoken, ... the type of investigation that has precipitated this lawsuit [is unlawful].

Following invalidation of HHS's Section 504 regulatory regime in this case, Congress weighed those interests and chose not to revive that regime. Instead, in the Child Abuse Amendments of 1984, note 20, *supra*, the Congress strengthened a state grant program and sought to help state child protective service agencies discharge their responsibilities in the context of severely impaired newborns.[59] A principal sponsor emphasized that: "This legislation does not itself authorize direct federal involvement in individual cases." *See* note 20, *supra* (letter of Sen. Hatch). In regulations implementing the new law, HHS has admitted that, in contrast to its Section 504 regulatory regime, Congress in the 1984 Child Abuse Amendments did not want a "new bureaucracy" created at the federal level to deal with treatment for impaired newborns; did not want creation of "federally prescribed medical standards for approved treatment of specific cases;" and did not want direct federal hotlines or other regulation of a hospital's internal affairs. 50 Fed. Reg. 14880, 14881, 14883-14884 (1985). HHS noted that the 1984 Amendments were "the product of an extraordinary effort" by Congres and medical,

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[59] *See* H.R. Conf. Rep. No. 1038, 98th Cong., 2d Sess. (1984) (federal grants to state child protective service agencies conditioned on incorporation of certain changes in state law and procedure).

"right-to-life" and disability groups "to forge a substantial consensus on an effective and workable program to assure" appropriate medical care for impaired newborns, concluding:

> It is clear that the legislation represented a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities. 50 Fed. Reg. 14879 (1985).

By contrast, HHS's 504 regulatory regime does not represent a careful balance by the Congress of the need to protect disabled infants and the need to avoid unreasonable governmental intervention into parental responsibilities and the practice of medicine. Indeed, the regulatory regime is far beyond anything remotely contemplated by the Congress and is clearly not authorized by Section 504. Accordingly, the judgment of the Court of Appeals should be affirmed.[60]

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[60] The judgment below (Pet. App. 50a-52a) enjoined HHS from (a) implementing the Final Regulation with respect to *individual treatment decisions* involving impaired newborns and (b) from otherwise investigating or regulating such decisions absent a specific regulation on the subject. Such decisions for impaired infants in individual cases are made only by parents and physicians. When parents do not consent to treatment for their child, Parts I and II, *supra*, have demonstrated that HHS has no authority to regulate parents' non-treatment decisions or physicians' duties under state law to report parental neglect. When parents do consent, Part III has demonstrated that HHS has no authority to regulate physicians' decisions. Accordingly, the judgment below should be affirmed and HHS should be enjoined from implementing the Final Regulation or otherwise regulating individual treatment decisions by parents or providers. As noted, the applicability of Section 504 to the enforcement practices of child protective service agencies is not presented by this case. *See* note 36, *supra*.

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In the Supreme Court of the United States

OCTOBER TERM, 1985

OTIS R. BOWEN, SECRETARY OF HEALTH AND HUMAN SERVICES, PETITIONER

v.

AMERICAN HOSPITAL ASSOCIATION, ET AL.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

REPLY BRIEF FOR THE PETITIONER

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ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

REPLY BRIEF FOR THE PETITIONER

Despite respondents' numerous diversions, this case presents a straightforward issue of statutory construction: whether Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, prohibits a federally funded hospital from withholding nourishment or medical treatment from a handicapped infant—or otherwise discriminating against the infant in the administration of its federally funded programs and activities—solely because of his handicap. The court of appeals held that Section 504 furnishes no protection to such an infant, and it therefore invalidated on their face the interpretative guidelines and regulations that the Secretary promulgated to give meaning and effect to Section 504 in this setting. The only question before this Court is whether that sweeping ruling by the court of appeals was correct. The application of Section 504 to any particular withholding of medical treatment is not presented here.

We have demonstrated in our opening brief that the language of Section 504 clearly prohibits a federally as-

sisted hospital from withholding nourishment or medical treatment from a handicapped infant solely because of his handicap. See Pet. Br. 16-28. We have further demonstrated that there is firm support for this interpretation at every stage in the evolution of Section 504—from its roots in Title VI of the Civil Rights Act of 1964, through its enactment in 1973, the amendments passed by Congress in 1974 and 1978, and the consistent administrative construction. See Pet. Br. 29-46.

Respondents American Medical Association, et al. (AMA), make essentially no effort to answer our arguments based on the text, legislative history, and administrative interpretation of Section 504. Moreover, by its own admission (AMA Br. 14-15 n.19), the AMA does not attempt to defend the legal reasoning of the court of appeals in striking down the interpretative guidelines and regulations on their face. The AMA instead devotes its brief primarily to two other matters that it believes would nevertheless support affirmance of the judgment below: the role of the parents in decisions concerning the furnishing of medical treatment to a child, and the duty of a hospital under state law to report suspected instances of medical neglect where the parents withhold their consent to such treatment. However, these issues are beside the point in this case, which concerns the role of the hospital, not the parents, and concerns the hospital's duty of non-discrimination under federal law, whether or not it complies with reporting obligations under state law.

By contrast, respondents American Hospital Association, et al. (AHA), do attempt to defend the court of appeals' broad holding, but to no avail. The AHA distorts the plain meaning of each of the statutory terms upon which it seizes in an effort to find some support for its resistance to the non-discrimination principle of Section 504, and the AHA fails to address those aspects of the legislative history and administrative interpretation of Section 504 that clearly establish its application to medical treatment decisions. But because the AHA does address at least some of the factors bearing on the ques-

tion of statutory construction presented in this case, we shall address its arguments first.

A. 1. The AHA first maintains (AHA Br. 17-18) that an infant born with severe impairments is not a "handicapped individual" for purposes of Section 504. Even the court of appeals rejected that contention (see Pet. App. 26a-28a), and with good reason. The term "handicapped individual" is defined to mean "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C. 706(7)(B). The AHA concedes (AHA Br. 18) that seriously ill infants have significant "physical or mental impairments" within the meaning of this definition, but it takes the position that these impairments are not relevant to "major life activities." This argument ignores reality.

The term "major life activities" is defined by HHS regulations first promulgated in 1977—the validity of which the AHA does not question—to mean "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 45 C.F.R. 84.3(j)(2)(ii). The AHA is wrong in arguing (AHA Br. 18) that this definition is concerned only with a person's ability to benefit from programs of education, employment, and independent living, and therefore does not apply to newborn infants. The illustrative list in the regulation refers to some functions (*e.g.*, seeing, hearing, breathing, and learning) that are relevant to *all* aspects of human existence, including that of infants (J.A. 61). The AHA's apparent argument to the contrary—that Section 504 is limited to adults and to children who have attained an age at which they are able to benefit from formal education—is refuted by the language of 29 U.S.C. 706(7)(B), which defines the term "handicapped individual" broadly to mean "*any* person," without limitation based on age. Moreover, this Court has stressed that Section 504 "protects handicapped persons of all ages." *Smith* v. *Robinson*, No. 82-2120 (July 5, 1984), slip op. 23.

2. The AHA argues (AHA Br. 18-20), however, that even if an impaired infant is a "handicapped individual," he is not "otherwise qualified," within the meaning of Section 504, to receive medical treatment from a federally assisted hospital. In the AHA's view, the term "otherwise qualified" means that in order for the non-discrimination requirement in Section 504 to apply, the individual's handicap must be an "irrelevancy," such that he has "essentially the same basic capabilities necessary for achievement in the same undertaking" as does a non-handicapped individual (AHA Br. 19). This argument fundamentally misapprehends the thrust of Section 504.

As this Court has held, an "otherwise qualified" handicapped individual is "one who is able to meet all of a program's requirements in spite of his handicap." *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979). The term thus refers to a person who satisfies whatever reasonably necessary and bona fide standards of general applicability are adopted by the federally funded program. Contrary to the AHA's contention, there is no additional prerequisite in Section 504 itself that the individual's handicap must be altogether irrelevant or that he have the same "basic capabilities" and potential for achieving a particular result as a non-handicapped person. See 45 C.F.R. 84.4(b)(2); *Alexander* v. *Choate*, No. 83-727 (Jan. 9, 1985), slip op. 16.

This interpretation is strongly supported by the legislative history of Section 504. The bills introduced in the 92d Congress, after which Section 504 was patterned (*Alexander* v. *Choate*, slip op. 7-8 n.13), would have amended Title VI of the Civil Rights Act of 1964 to bar discrimination against a person on the basis of handicap "unless lack of such physical or mental handicap is a bona fide qualification reasonably necessary to the normal operation of such program or activity." S. 3044, 92d Cong., 2d Sess. (1972); 118 Cong. Rec. 526 (1972); see 118 Cong. Rec. 2999 (1972) (remarks of Rep. Vanik). See also 124 Cong. Rec. 30323-30324, 37509-37510 (1978) (remarks of Sen. Williams). This provision obviously is

the source of the term "otherwise qualified" in Section 504 as eventually enacted. The AHA does not suggest that the lack of the handicaps experienced by the infants who are protected by the guidelines and regulations at issue here is in all instances "a bona fide qualification reasonably necessary to the normal operation" of a federally assisted hospital program. Nor could it plausibly do so. Indeed, the AMA baldly asserts (AMA Br. 40) that a hospital would *never* decline to furnish medically indicated treatment to a handicapped infant where the parents have given their consent, and a necessary premise of that assertion is that the hospitals concerned do regard such an infant as "otherwise qualified" for medical treatment. At the very least there is no basis for the AHA's argument that *all* such infants are categorically excluded from the coverage of Section 504 because they are not "otherwise qualified" to receive the medical benefits of the federally assisted health program.

3. a. In an effort to avoid entirely any prohibition against discrimination, the AHA next argues (AHA Br. 21-25) that a hospital does not receive the sort of "federal financial assistance" that triggers the application of Section 504. However, this issue cannot be resolved in the context of this broad challenge to the interpretative guidelines and regulations on their face. The guidelines and regulations do not even address the question of what constitutes a program or activity receiving federal financial assistance for purposes of Section 504. Moreover, neither court below considered whether, as a general matter, hospitals have programs or activities that make Section 504 applicable in this setting, because both courts concluded that Section 504 has no application to medical treatment decisions affecting handicapped infants even in a program that receives federal financial assistance. For these reasons, whether any particular hospital receives federal financial assistance within the meaning of Section 504 would more appropriately be considered in the context of the application of Section 504 to a medical treatment decision made in that institution. See Pet. App. 16a-18a; *United States* v. *Baylor University Medical*

Center, 736 F.2d 1039, 1041 n.2 (5th Cir. 1984), cert. denied, No. 84-525 (Jan. 21, 1985).

b. In any event, the AHA's broad argument that Section 504 could never apply to the treatment of handicapped infants because, as a matter of law, a hospital never receives "federal financial assistance" that triggers its application in this setting was fully considered and correctly rejected by the Secretary when the guidelines and regulations were promulgated (J.A. 69-75). It is important to stress that the AHA's argument apparently also would render Title VI of the Civil Rights Act of 1964 largely inapplicable to federally funded hospital programs, despite their receipt of approximately $48 billion annually under the Medicare and Medicaid programs (J.A. 72). Yet the legislative history of the Civil Rights Act of 1964 establishes that Title VI was intended to apply to the predecessor of the Medicaid Program (110 Cong. Rec. 13132 (1964) (#41); *id.* at 1661 (remarks of Rep. Lindsay, et al.)), and the 1965 amendments to the Social Security Act in which the Medicare and Medicaid programs were enacted make clear that Congress intended that Title VI would apply to hospitals that receive financial assistance under those programs (111 Cong. Rec. 15803 (1965) (remarks of Sen. Ribicoff); *id.* at 15813 (remarks of Sens. Hart and Pastore)). See Pet. Br. 30-31; *Baylor University Medical Center*, 736 F.2d at 1044-1046.

Moreover, prior to the enactment of Section 504 in 1973, the Secretary had promulgated regulations making clear that Title VI prohibits discrimination on the basis of race in the admission and treatment of patients in federally funded health programs (45 C.F.R. 80.4(d)(2) and 80.5(a) (1966)) and that Medicaid and Medicare are to be regarded as federal financial assistance for these purposes (45 C.F.R. Pt. 80, App. A, pt. 1 para. 121 and pt. 2 para. 30, as added by 38 Fed. Reg. 17984 (July 5, 1973)). Because Congress patterned Section 504 after Title VI (see Pet. Br. 30, 35-36), Congress must be presumed to have intended that Medicare and

Medicaid would constitute federal financial assistance under Section 504 as well. See *Cannon* v. *University of Chicago*, 441 U.S. 677, 694-698 (1979); *Lorillard* v. *Pons*, 434 U.S. 575, 580-581 (1978).

When the regulations implementing Section 504 were promulgated in 1977, the Secretary again took the position that the Medicaid and Part A Medicare programs constitute federal financial assistance for these purposes (see 45 C.F.R. Pt. 84, App. A, paras. 1 and 2), and the legislative history of the 1978 amendments to the Rehabilitation Act confirms the correctness of that interpretation (124 Cong. Rec. 30325 (1978) (remarks of Sen. Hathaway)). See also H.R. Rep. 98-442, 98th Cong., 1st Sess. 77 (1983). Nor did this Court in *Alexander* v. *Choate* question the applicability of Section 504 to the furnishing of services under Medicaid. Against this background, there is no merit whatever to the AHA's argument (AHA Br. 21-22) that the interpretative guidelines and implementing regulations at issue here are invalid on their face because Medicare and Medicaid cannot, as a matter of law, constitute federal financial assistance.[1]

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[1] Several related arguments by the AHA warrant a brief response. The AHA asserts (AHA Br. 23) that the receipt of Medicare funds does not trigger the application of Section 504 because Medicare funds are paid only on behalf of the aged and disabled, not infants. This argument is premised on the view that the relevant "program" for purposes of Section 504 is confined to those particular subparts of the hospital's inpatient operations in which specific Medicare patients are housed, rather than the inpatient operations as a whole. But see *Baylor University Medical Center*, 736 F.2d at 1041 n.2, 1050. But even if only subparts of the hospital's inpatient operations are covered, the receipt of Medicaid funds for services rendered in the subpart in which impaired infants are treated would make Section 504 applicable.

The AHA also asserts (AHA Br. 23-24) that the application of Section 504 to the discriminatory withholding of medical treatment from a handicapped infant would be inconsistent with 42 U.S.C. 1395, which provides that nothing in the Medicare Act shall be construed to authorize any federal officer "to exercise any supervision or control over the practice of medicine" or over the administration of any institution furnishing health services. See also

4. The AHA also contends (AHA Br. 28-31) that the denial of nourishment or needed medical treatment to a handicapped child cannot, as a matter of law, constitute "discrimination" within the meaning of Section 504. Embracing the view of the court of appeals in the *University Hospital* case, the AHA argues that "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'" (AHA Br. 29, quoting Pet. App. 30a).

AMA Br. 39 n.48. This argument is without merit for two reasons. First, by its terms, 42 U.S.C. 1395 refers only to the Medicare Act; it does not apply to the exercise of authority under other statutes, such as Title VI or Section 504, that impose duties of nondiscrimination in the furnishing of medical care. Second, 42 U.S.C. 1395 does not prohibit the scrutiny of medical services even in the administration of the Medicare program—*e.g.*, to determine whether services for which reimbursement is sought were reasonable and necessary. See *Szekely* v. *Florida Medical Association*, 517 F.2d 345 (5th Cir. 1975), cert. denied, 425 U.S. 960 (1976).

Finally, the AHA's argument (AHA Br. 26-28) that Section 504 can never apply in this setting because hospitals do not actually make treatment decisions in particular cases is without merit. In the first place, Section 504 requires the hospital to respond in a non-discriminatory manner when it learns of a withholding of necessary medical treatment for a handicapped infant who is a patient in the hospital, even if it exercises no control over the actions of physicians to whom it has granted staff privileges. In any event, hospitals have the authority to insist that physicians who are granted staff privileges adhere to medical and ethical standards. See *Lew* v. *Kona Hospital*, 754 F.2d 1420, 1424 (9th Cir. 1985); *Truly* v. *Madison General Hospital*, 673 F.2d 763, 765 (5th Cir.), cert. denied, 459 U.S. 909 (1982); *Sosa* v. *Board of Managers of Val Verde Memorial Hospital*, 437 F.2d 173 (5th Cir. 1971). In fact, the Medicare regulations require that the hospital have an organized medical staff that is "responsible to the governing body of the hospital for the quality of all medical care provided patients in the hospital and for the ethical and professional practices of its members" (42 C.F.R. 405.1023). See also 42 C.F.R. 405.1021. The Secretary's Section 504 regulations also make clear that the recipient of federal financial assistance is prohibited from discriminating on the basis of handicap "through contractual, licensing, or other arrangements" and from aiding discrimination practiced by others. 45 C.F.R. 84.4(b)(1) and (v), 84.5(a). See J.A. 64-66.

This argument is seriously flawed in two critical respects. First, it wholly ignores the not infrequent situation in which the handicapping condition is not inextricably related to the condition for which a particular course of treatment is otherwise indicated. For example, in the case of a child who has Down's Syndrome and a blocked esophagus, the presence of the handicapping condition (Down's Syndrome) does not suggest that surgery to correct the blocked esophagus is contraindicated as a medical matter. Cf. *Guardianship of Philip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983).[2]

Second, the AHA's argument ignores the fact that the non-discrimination principle embodied in Section 504 is not rendered nugatory simply because several conditions may be interrelated and must be treated in a coordinated fashion. As the Secretary explained when the guidelines were promulgated, the same analytical framework applies in such a case: the "handicap" is the physical or mental impairment that would remain *after* completion of the treatment for a particular aspect of the infant's condition, and the provider may not withhold that treatment solely because the infant would have that handicap after the treatment was completed (J.A. 62-64).

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[2] The AHA relies (AHA Br. 29) on recent testimony before the Civil Rights Commission. However, in those hearings, the Surgeon General upon whose testimony the AHA relies (AHA Br. 29, 30), made clear that the AHA's example of inextricably interrelated impairments does not describe the actual circumstances in all cases. He stated that if the esophegal problem in the Bloomington child had been present in a child who did not have Down's Syndrome, it "would have been corrected surgically and would have likely had about a 95 percent success rate. But when the two [Down's Syndrome and esophegal atresia] exist together, it provides an opportunity for one to influence the treatment of the other, and hence the initial concern that children who were so treated were, in a sense, having their civil rights violated." *Protection of Handicapped Newborns: Hearings Before the United States Commission on Civil Rights* 8 (June 12, 1985).

It may be that in certain cases involving several interrelated medical problems, there will be a relatively broad range of reasonable medical judgments that might be made regarding what (if any) treatment should be afforded to the infant. The interpretative guidelines at issue here do not intrude the Secretary into these complex medical judgments. Section 504 instead states a single guiding principle that may readily be borne in mind by the hospital, treating physicians and other responsible personnel: the decision whether or how to treat a handicapped infant must be based on a bona fide medical judgment regarding the risks and benefits to the infant, and not on the mere fact that he is handicapped and may remain so after the treatment. Section 504 therefore does nothing more than require that medical professionals actually exercise the same sort of medical judgment on behalf of their patients who are handicapped infants that, as the AHA and AMA concede (AHA Br. 31; AMA Br. 6, 40, 46), they are legally and ethically bound to exercise on behalf of their patients who are not handicapped. Compare *Youngberg* v. *Romeo*, 457 U.S. 307, 323 (1982). The Secretary has repeatedly made clear that such bona fide medical judgments by medical professionals will be respected (J.A. 12-13, 19, 41).

5. As we have shown above and in our opening brief (at 18-28), the language of Section 504 clearly prohibits a federally assisted hospital program from denying a handicapped infant nourishment, medical treatment, or other benefits solely because of his handicap. That language must control "[a]bsent a clearly expressed legislative intention to the contrary" (*Consumer Product Safety Commission* v. *GTE Sylvania, Inc.*, 447 U.S. 102, 108 (1980)). The AHA's discussion of the legislative history of Section 504 (AHA Br. 32-40) fails to identify *any* indication of a contrary congressional intention.

a. The AHA first ignores both the legislative history of Title VI, which manifests a clear intent to prohibit

"[d]iscriminatory treatment of patients" in federally assisted hospitals (110 Cong. Rec. 6546 (1964) (remarks of Sen. Humphrey)), and the Title VI regulations, which from the outset have prohibited discrimination on the basis of race with respect to "admission *or* other treatment of individuals as * * * patients" (45 C.F.R. 80.4 (d) (2) (emphasis added)). See Pet. Br. 30-31. Against this background, it is clear that Title VI prohibits racial discrimination not only in the admissions policies of hospitals, as the AHA suggests (AHA Br. 33), but also in the subsequent furnishing of medical treatment to patients who were initially admitted on a non-discriminatory basis.

The AHA concedes (AHA Br. 31-32 n.32), as does the AMA (AMA Br. 42, 43 n.55), that Section 504 bars a hospital from discriminating in connection with the admission of patients in a federally assisted health services program—*i.e.*, in providing "access" to such a program. Because Section 504 was patterned after Title VI, it follows, if this much is conceded, that Section 504 likewise must be construed to require the "even-handed treatment" (*Alexander* v. *Choate*, slip op. 16) of a handicapped infant after he has been admitted to the hospital. The text of Section 504 compels that conclusion: it provides that an otherwise qualified handicapped individual shall not, solely by reason of his handicap, "be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Although the first of these three phrases might prohibit discrimination only in a hospital's admission of patients to a hospital's federally assisted programs (and similar matters of "access"), the latter two phrases plainly prohibit discrimination in the hospital's furnishing of medical services to infants who have been admitted. Moreover, as the Secretary explained in promulgating the regulations, "it is an anomalous and bizarre theory that section 504 can properly be used to require that a ramp be built in a hospital to assure that

handicapped persons not be denied access to medical services solely on the basis of their handicaps, but that statute may not properly be used to prevent the intentional act of allowing other handicapped persons to die in that hospital, solely because of their handicaps" (J.A. 62).

b. The AHA's efforts (AHA Br. 34-38) to find specific support in the legislative history of Section 504 for an implied exemption for medical treatment decisions also is without merit. Contrary to the AHA's assertion (AHA Br. 34-36) that Senator Humphrey was concerned only with educational opportunities for handicapped children, the Senator stated that "[e]very child—gifted, normal and handicapped—has a fundamental right to educational opportunity *and* the right to health" (118 Cong. Rec. 526 (1972) (emphasis added)). Further, as the AHA concedes (AHA Br. 36-37 & n.39), Senator Percy linked the predecessor to Section 504 to a Senate Resolution that called for a declaration of rights of the handicapped, including the "right to proper medical care" (S. Con. Res. 92 Cong., 1st Sess. (1971); 117 Cong. Rec. 42294 (1971)). See 118 Cong. Rec. 526, 11789 (1972) (remarks of Sen. Percy).[3]

c. The AHA wholly ignores the legislative history of the 1974 amendment of the term "handicapped individual" that unambiguously demonstrates a congressional intent to establish a "broad governmental policy" against dis-

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[3] The AHA also takes issue (AHA Br. 38 n.43) with our quotation of Representative Vanik's reference to the practice of the ancient Spartans of leaving a "handicapped newborn * * * to die of exposure on the mountainside" and his rhetorical question: "Are we guilty of the same type of gross neglect in this country?" (119 Cong. Rec. 18137 (1973)). The AHA attempts to discount the relevance of this comment because it was made in connection with an objection to the elimination of certain provisions for educational assistance for handicapped children. The AHA misses the point. Representative Vanik obviously found the Spartan's treatment of handicapped newborns abhorrent. It is reasonable to assume that he also would have found abhorrent any comparable modern-day practice, such as allowing a handicapped newborn to die in a hospital as a result of the denial of necessary medical treatment.

crimination in federally assisted programs (S. Rep. 93-1297, 93d Cong., 2d Sess. 39 (1974)); that the programs Congress had in mind specifically included those furnishing "health services" (*id.* at 38); that discrimination on the basis of handicap should be regarded as "similar to discrimination because of race" (*ibid.*); and that the Secretary should issue regulations to implement Section 504 (*id.* at 39-40). As we have explained (Pet. Br. 35-36), each of these aspects of the 1974 legislative history strongly supports the Secretary's interpretation of Section 504 as barring discrimination on the basis of handicap in the furnishing of medical services to handicapped infants, just as Title VI bars discrimination on the basis of race in the furnishing of medical services. At the very least, this legislative history does not furnish affirmative support for the AHA's argument (AHA Br. 38 & n.44) that Section 504 should be construed, contrary to its plain language, to bar discrimination only in "access" to federally assisted programs.[4]

The AHA also ignores the obvious significance of Congress's parallel enactment in 1974 of the prohibition against discriminatory treatment of alcoholics by a hospital. See Pet. Br. 38-40. Contrary to the AHA's suggestion elsewhere in its brief (AHA Br. 25-26 n.25, 40 n.46), this prohibition is not limited to discrimination in the admission of patients. The statutory provision explicitly bars discrimination in "admission *or* treatment" (Pub. L. No. 93-282, § 121(a), 88 Stat. 130; 42 U.S.C. (Supp. I) 290dd-2(a) (emphasis added)). See also S. Rep. 93-208, 93d Cong., 1st Sess. 14 (1973).

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[4] The AHA relies on the example in the 1974 Senate Report of "handicapped persons who may be denied admission to Federally-assisted nursing homes on the basis of their handicap" (S. Rep. 93-1297, *supra*, at 38). See also AMA Br. 43 n.55. However, this example in no way suggests an affirmative intent by Congress to allow a federally assisted nursing home or other provider of health services to withhold necessary medical or other services from an otherwise qualified handicapped person who already had been admitted to its care. See *Jefferson County Pharmaceutical Ass'n* v. *Abbott Laboratories*, 460 U.S. 150, 159 n.18 (1983).

d. Finally, the AHA concedes (AHA Br. 40 & n.46) that the Section 504 regulations promulgated by the Secretary in 1977 barred discrimination in the furnishing of medical treatment as a general matter; specifically prohibited discrimination by federally assisted hospitals in the admission and "treatment" of alcoholics and drug addicts; and discussed the Attorney General's opinion concluding that Section 504 prohibits discrimination in medical treatment. See Pet. Br. 40-42; 45 C.F.R. 84.51 and 84.53; *id.* Pt. 84, App. A, paras. 4, 36, 37. The AHA argues (AHA Br. 40 & n.46), however, that Congress's enactment of the 1978 amendments to the Rehabilitation Act cannot be viewed as an endorsement of this administrative interpretation. The AHA is wrong for two reasons.

First, contrary to the AHA's assertion, this Court in *Consolidated Rail Corp.* v. *Darrone*, 465 U.S. 624 (1984), read the 1978 amendments to reflect approval not only of the procedural provisions of the Section 504 regulations, but also their substantive provisions—including those involved in *Darrone* itself that barred discrimination in employment regardless of the primary objective of the federal financial assistance. See 465 U.S. at 634-635 & nn. 14-16. Second, as we have explained (Pet. Br. 42-43), the legislative history of the 1978 amendments shows a clear congressional awareness and general endorsement of the views of the Secretary and the Attorney General and an understanding that Section 504 bars discrimination in the furnishing of health services by hospitals and other providers.

B. 1. The AMA, in contrast to the AHA, makes essentially no effort to respond to our arguments based on the text and legislative history of Section 504 or to defend the court of appeals' reasoning in creating an implied exception from Section 504 for discrimination in the furnishing of health services to handicapped infants. In fact, the AMA appears to concede (AMA Br. 42, 43) that Section 504 prohibits a federally assisted hospital from adopting a general policy of refusing to treat handicapped persons because of their handicaps. It argues

(AMA Br. 43-47), however, that a decision in an individual case to deny needed medical treatment to a handicapped infant solely because of his handicap—even where the parents have consented to such treatment—is beyond the reach of Section 504. And the AMA so argues even though it acknowledges (AMA Br. 46, 42) that such conduct would be "scandalous" and violate the law of all 50 states.

The AMA cites nothing—and there is nothing—in the text, legislative history, or purposes of Section 504 to support the AMA's proffered distinction between a discriminatory policy of refusing to furnish medical treatment to handicapped persons generally and a discriminatory refusal in an individual case. To the contrary, the AMA's argument flies in the face of the statutory language, which provides that "[n]o otherwise qualified *individual* * * * shall, solely by reason of *his* handicap * * * be denied the benefits of, or be subjected to discrimination" under a federally assisted program (emphasis added). The statute thus explicitly refers to individual acts of discrimination, not merely discriminatory policies of general application. See *Regents of the University of California* v. *Bakke*, 438 U.S. 265, 414-418 (1978) (opinion of Stevens, J.); cf. *Connecticut* v. *Teal*, 457 U.S. 440, 453-456 (1982). Compare 45 C.F.R. 84.4 (b)(1) with *id.* 84.4(b)(4). It would be no solace to a handicapped individual who was denied treatment because of his own handicap to learn that the hospital does not have a broad policy of denying treatment to handicapped persons generally.[5] Accordingly, Section 504

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[5] Contrary to the AMA's assertion (AMA Br. 43), the example contained in the explanatory analysis of the Section 504 regulations promulgated in 1977 is not limited to general policies of exclusion (45 C.F.R. Pt. 84, App. A, para. 36 (emphasis added)):

> [A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such treatment to nonhandicapped persons. It could not, however, refuse to treat the burns of *a deaf person* because of his or her deafness.

See also 45 C.F.R. 84.53.

clearly prohibits a federally assisted hospital from refusing to furnish medical treatment to any particular handicapped infant, solely because of his handicap, where the parents have given their consent to the treatment.[6]

2. a. The AMA argues (AMA Br. 19-38), however, that Section 504 has no application where the parents have withheld their consent to treatment. The AMA first argues that because the Secretary acknowledges that Section 504 does not impose any duties on parents, since they are not recipients of federal financial assistance (J.A. 43, 122), the guidelines constitute an illegal attempt to accomplish indirectly what the Secretary cannot

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[6] The AMR argues (AMA Br. 39-41) that the guidelines and regulations are invalid under the Administrative Procedure Act, 5 U.S.C. 706(2)(A), to the extent they address a hospital's refusal to furnish treatment where the parents have consented to the treatment, because the Secretary did not establish as a factual matter that such refusals have occurred in the past. This argument is without merit for several reasons. First, although the AMA is correct in pointing out (AMA Br. 39 n.47) that it did include an APA count in its complaint, the AMA's objection in that count was limited to the asserted absence of a factual basis for the regulation insofar as it applies to situations in which the parents have *not* given their consent to treatment. See J.A. 146-147. The APA argument the AMA raises therefore is not properly before this Court.

Second, as the Secretary has explained (J.A. 34), the 1984 regulations did not establish the application of Section 504 to the discriminatory withholding of medical treatment from handicapped infants; that application already was established by Section 504 itself and the 1977 regulations. The principal feature of the measures adopted in 1984 was the interpretative guidelines, which merely explained the Secretary's construction of Section 504 in this setting. See 45 C.F.R. Pt. 84, App. C. Those guidelines imposed no new substantive duties on federally assisted hospitals. Compare *Motor Vehicle Manufacturers Ass'n* v. *State Farm Mutual Automobile Insurance Co.*, 463 U.S. 29, 40-42 (1983). The Secretary need not establish a factual basis for the issuance of guidelines interpreting the statute. Cf. 5 U.S.C. 553(b)(B).

accomplish directly. See AMA Br. 19-24, 38. This argument is without merit.[7]

The Court has recognized that a state "is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized." *Parham* v. *J.R.*, 442 U.S. 584, 603 (1979); see also *Santosky* v. *Kramer*, 455 U.S. 745 (1982). Accordingly, as the AMA concedes (AMA Br. 3-4, 25), the law of all 50 states provides for the overriding of the parents' withholding of consent to medical treatment in some circumstances and permits (indeed requires) a hospital to take steps to facilitate such state intervention in appropriate circumstances—*e.g.*, by reporting the matter to the responsible state agency or instituting its own judicial action in state court. See Pet. Br. 28 n.17. Section 504 simply requires that the hospital act in a nondiscriminatory manner in response to the parents' action by taking such steps for the protection of a handicapped child if it would do so in similar circumstances for a nonhandicapped child. Nor does Section 504 affirmatively prohibit the Secretary from taking steps that may have

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[7] Contrary to the AMA's assertion (AMA Br. 7-10), the Secretary made clear from the outset that Section 504 does not authorize the regulation of parents' decisions concerning the treatment of their children. See 47 Fed. Reg. 26027 (1982) (J.A. 127-128). Moreover, and again contrary to the AMA's assertion (AMA Br. 21-23, 38), there is no inconsistency between that position and the Secretary's bringing of the action against the hospital in the *University Hospital* case to obtain access to the hospital's records pertaining to Baby Jane Doe. Without access to those records, HHS could not determine whether the *hospital* had engaged in discrimination on the basis of handicap in its response to the parents' withholding of consent to treatment. The AMA also errs in asserting that the requirement that the hospital post a notice "is unquestionably aimed at parents" (AMA Br. 23). The Secretary modified this requirement for the express purpose of permitting it to be posted where it would not be conspicuous to parents but would be conspicuous to hospital personnel (J.A. 25).

an effect on parental decisions, because there is no congressional policy in Section 504 to afford absolute deference to those decisions.[8] Section 504 simply does not address parents' decisions as such, because parents are not recipients of federal financial assistance within the meaning of the statute. Moreover, if the hospital takes appropriate steps in response to the parents' withholding of consent, it is the state law processes the hospital invokes, not Section 504, that overrides the parents' wishes.

b. The AMA also argues (AMA Br. 24-38) that, in order to avoid the need for the Secretary to make state-law determinations, no violation of Section 504 may be found in parental non-consent situations in the absence of a prior determination by state authorities that the hospital has violated its duties under state law to report suspected incidents of medical neglect by parents. Contrary to the AMA's contention (AMA Br. 25-27), however, a violation of Section 504 in these circumstances is not dependent upon a finding of a violation by the hospital of a state-law reporting duty. The Secretary's guidelines provide that where the parents have withheld their consent, the hospital still must operate all aspects of its health care programs in a manner consistent with Section 504. The guidelines then state (J.A. 122 (emphasis added)):

> Such aspects include[] decisions on whether to report, as required by State law *or otherwise*, to the appropriate child protective services agency a suspected instance of medical neglect of a child, or to take other action [*e.g.*, filing its own judicial action] to seek review [of] parental decisions to withhold consent for medically indicated treatment.

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[8] Again, an analogy to Title VI is instructive. Although a parent might want his child to be placed in a racially segregated classroom or to be treated differently because of his race, Title VI clearly would prohibit a school district that receives federal financial assistance from complying with the parent's wishes. Similarly here, the parents' wishes do not relieve the hospital from its duty to conduct its affairs in a non-discriminatory manner.

The emphasized words, which the AMA conspicuously omits in its quotation of the guidelines (AMA Br. 26), make clear that the guidelines prohibit discrimination in the hospital's response to a parental withholding of consent, whether or not the hospital's actions also violate state law. For example, Section 504 requires evenhanded treatment of a handicapped person in the application of the hospital's own internal policies and procedures that are to be followed in the case of the refusal by parents to consent to necessary treatment for their child.[9]

The result is no different, however, where the hospital's failure to report the matter to the state agency or to file a judicial action does violate state law. There are many situations in which state law forms a backdrop for the actions of an entity (*e.g.*, a school district or police department) that is subject to the nondiscrimination requirements of the federal civil rights laws. It has never been thought that federal officials are disabled from investigating allegations of discrimination in the operation of such entity unless and until state authorities have determined that the conduct in question also violated state law. The federal interest is not in the violation of state law as such, but in the distinct violation of federal law resulting from the hospital's discriminatory conduct.

Of course, if HHS learns of a situation in which a hospital failed to notify the responsible agency or take other customary action where the parents have withheld their consent to treatment, it may be appropriate in many circumstances for HHS to notify the responsible state agency and to defer in the first instance to the state agency, which can determine whether the parents' withholding of consent constituted child neglect or whether a

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[9] The AMA also relies on 45 C.F.R. 84.55(c). See AMA Br. 25-26, 30 n.37. However, that provision does not address the responsibilities of hospitals under Section 504. It concerns the distinct responsibilities of a state child protective services agency that receives federal funds to utilize its authority under state law to investigate instances of medical neglect of handicapped infants.

hospital's failure to report the incident violated a state law duty. See 48 Fed. Reg. 30849 (1983). When the regulations implementing the Child Abuse Amendments of 1984 were promulgated, the Secretary stressed that if this Court holds that Section 504 applies to the withholding of medical treatment from handicapped infants, steps will be taken to ensure that the requirements under the 1984 Amendments that state agencies investigate the withholding of medical treatment from handicapped infants will be "fully coordinated" with the implementation of Section 504 (50 Fed. Reg. 14885 (1985)).[10]

For the foregoing reasons and those stated in our opening brief, the judgment of the court of appeals should be reversed.

Respectfully submitted.

CHARLES FRIED
Solicitor General

JANUARY 1986

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[10] Although both the AMA and AHA assert that HHS investigations have been disruptive (AMA Br. 33-34; AHA Br. 7-10, 27-28), the Secretary refuted those assertions when the regulations were promulgated (J.A. 80-86). The Secretary also prescribed guidelines to minimize the number of on-site investigations and to ensure that future federal investigations will be conducted with the least disruption possible. 45 C.F.R. Pt. 84, App. C, subpt. (b). See J.A. 46-56. Any remaining issues regarding the manner in which such investigations are conducted should be resolved on a case-by-case basis, if and when they arise.

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IN THE
Supreme Court of the United States
OCTOBER TERM, 1985

MARGARET M. HECKLER, Secretary of Health and Human Services,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF AMICI CURIAE THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES; NATIONAL DOWN SYNDROME CONGRESS; SPINA BIFIDA ASSOCIATION OF AMERICA and FUND FOR EQUAL ACCESS TO SOCIETY IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

MARGARET M. HECKLER, Secretary of Health and Human Services,

Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF AMICI CURIAE THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES; *et. al.*, IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

INTEREST OF AMICI CURIAE [1]

Amici are organizations of parents of children who are disabled and of disabled adults and others who have been and continue to be directly affected by and actively interested in the enforcement of Section 504 of the Rehabilitation Act of 1973 by Petitioner, Margaret M. Heckler, with respect to the rights afforded to handicapped infant patients under that Act to an equal opportunity to receive the same type of beneficial medical treatment routinely provided to non-handicapped infant patients. The membership of these organizations include large numbers of

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[1] All parties have consented to the filing of this brief.

parents of children with the types of disabilities that have most frequently been the basis of decisions to withhold beneficial medical treatment on the basis of handicap.

The ASSOCIATION FOR RETARDED CITIZENS of the UNITED STATES is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately six million retarded citizens. Its national membership numbers over 150,000 people, more than half of whom are parents of retarded children and adults, and includes people who are mentally retarded themselves. ARC/US has chapters in 49 of the 50 states and 1,300 local chapters in cities, counties and towns across the country. Since its founding in 1950, ARC/US has participated actively in the formulation of public policy respecting the rights of and services for retarded citizens and has been recognized in every forum, including the Congress, state legislatures, rulemaking proceedings, and in the courts, as fairly and fully representative of the interests of retarded citizens and their families. ARC/US participated in the congressional formulation and passage of Section 504 of the Rehabilitation Act of 1973 and its amendments.

The NATIONAL DOWN SYNDROME CONGRESS is a voluntary organization of parents and families of people with Down's syndrome. Established as a national organization in 1974, the National Down Syndrome Congress is a network of more than 600 parent groups serving the needs of families in their local communities. Among its official purposes are "[to] address the social policies and conditions that limit the full growth and potential of children and adults with Down Syndrome." Its monthly publication, *Down's Syndrome News*, reaches 50,000 people.

The SPINA BIFIDA ASSOCIATION OF AMERICA was founded in 1972 to foster and promote the human rights of all people having the condition known as spina

bifida (or open spine at birth). Its national membership comprises 10,000 families and professionals. In 1979 the Association adopted a position in favor of the early evaluation and medical/surgical treatment of every infant born with spina bifida.

The FUND FOR EQUAL ACCESS TO SOCIETY is a non-profit corporation founded in 1980 to promote social and economic opportunities for persons with disabilities. During the last five years the Fund has provided assistance to over one hundred Federal, state and local health and education agencies in the planning, development, drafting and implementation of state laws, regulations, interagency agreements and policies designed to carry out the requirements of Section 504 of the Rehabilitation Act of 1973.

SUMMARY OF ARGUMENT

This case presents the narrow question of whether Congress in enacting the broad statutory language of Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap in the operation of programs receiving Federal financial assistance, intended to exclude handicapped infants or children from such protection insofar as the provision of life-sustaining medical treatment is concerned.

A review of the history of the discrimination against children with disabilities that prompted Amici and other national parent organizations to press Congress for the enactment of Section 504 reveals numerous instances of the denial of equal opportunity to beneficial medical treatment and health care to handicapped patients. This inequality in the provision of health care services, thus, was an important part of the overall pattern of bias and discrimination which Congress sought to prohibit through the enactment of the statute. The legislative history surrounding the passage of Section 504 directly supports its applicability to the discriminatory denial of health care

services, as does the clear congressional intent to track Title VI of the Civil Rights Act of 1964 which, for over twenty years, has prohibited, without exception, all types of discrimination in the provision of medical care and treatment. This Court need only determine whether, given the parallel wording of Section 504 and Title VI, there is any textual basis for adopting a radically different interpretation with respect to discrimination on the basis of handicap.

Decisions to withhold beneficial medical treatment from infants have most frequently been made by health care providers on the basis of non-medical, sociological criteria and then suggested to parents in a manner that results in the parents' inability to provide informed consent. These sociological judgments of physicians who discriminate have been presented variously to parents as medical judgments or as no-treatment recommendations or alternatives despite the fact that often no good faith question exists as to the proper course of medical treatment beneficial to the life and health of the infant. Physicians have frequently denied parents crucially important information regarding the medical condition and developmental capabilities of their children and have often required parents to hurriedly acquiesce in no-treatment "recommendations" during a period of psychological crisis. Thus, the consent provided by parents presented with such judgments and no-treatment alternatives often lacks the "voluntariness" required by the Common Law. In many situations the actual decision to terminate the life of the handicapped infant patient is made by a physician on the basis of sociological factors. This distortion of the traditional role of the physician in our society—a role based on trust in the implicit assumption that the physician always seeks to act in the best interests of the patient—is precisely the type of discrimination which the civil rights laws are designed to prohibit.

ARGUMENT

I. CONGRESS INTENDED SECTION 504 TO PROHIBIT THE DENIAL TO HANDICAPPED PERSONS OF THE BENEFICIAL MEDICAL TREATMENT ROUTINELY PROVIDED TO NON-HANDICAPPED PERSONS.

In *City of Cleburne, Texas* v. *Cleburne Living Center*, 105 S.Ct. 3249 (1985), Justice Stevens and the Chief Justice (concurring) described a "history of unfair and often grotesque mistreatment" imposed "through prejudice and ignorance" against mentally retarded children and adults. *Id.* at 3262. Justice Marshall, in describing this "regime of state mandated segregation and degradation" specifically referred to the link between this regime and prominent members of the medical profession:

> "Fueled by the rising tide of Social Darwinism, the 'science' of eugenics, and the extreme xenophobia of those years, leading medical authorities and others began to portray the 'feebleminded' as a menace to society and civilization . . . responsible in large degree for many if not all of our social problems." *Id.* at 3266.

In *Cleburne* this Court declined to apply heightened scrutiny to classifications disadvantageous to mentally retarded persons on the ground that legislative responses, including the enactment of Section 504 of the Rehabilitation Act of 1973, belie "a continuing antipathy or prejudice" toward mentally retarded persons. *Id.* at 3256. In this case, the question before this Court is whether this same statute forbids the denial to handicapped infants by Federally supported health care providers of critical medical care and treatment which would routinely be provided to non-handicapped infants without consideration of sociological projections or judgments.

A. Physicians Treat Parents of Infants with Life-Threatening Conditions Differently Depending on Whether the Infant Is or Is Not Handicapped.

In the normal course of medical practice, it is usually the physician and not the patient (or parents of the patient) who frames and requests treatment decisions.[2] The experience of Amici, as parents of handicapped children, has been that some physicians act differently towards parents who have infants with identical medical problems based on whether or not the infant is expected to be a handicapped child and adult. Often the very framing of a parental treatment/no-treatment decision by a physician reveals an underlying difference in assumptions regarding the value of the life of the handicapped infant. If a parent takes a sick, non-handicapped child to a hospital for an examination which reveals that the child has a life-threatening infection easily and safely cured by an injection of antibiotics, would any physician seriously ask the parent the question of whether the vitally needed medical treatment should be withheld? Physicians, however, frequently call upon parents of sick, handicapped infants to make such decisions. Parents of infants with spina bifida have been asked to consent to the withholding of antibiotics from their handicapped children with life-threatening infections.[3] In this situation, the physician

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[2] This case concerns the denial of medical assistance to a child who, if given medical assistance, will live and will have a life-long disability. It does *not* raise any questions concerning the withholding of medical assistance which would only prolong dying. Those persons covered by the statute at issue here include both handicapped children who require routine, life-saving surgery to correct a common, unrelated health problem (e.g., the blockage of an esophagus or a heart condition of a Down's syndrome child) and children whose handicapping condition (e.g., spina bifida) could directly contribute to their death if routine surgery or medical treatment (e.g., antibiotics) is withheld or unduly postponed.

[3] Physicians have withheld antibiotics from now deceased infants with spina bifida on the basis of sociological criteria unrelated to their medical condition. Gross, et al., *Early Management and*

suggests to parents a decision which assumes that the withdrawal of a routine medical procedure needed to preserve the life of a handicapped child is acceptable, despite the fact that such a decision would never even be suggested if an infant with the same infection were not handicapped. The *a priori* assumption of such a question is not that the child cannot or will not live, but rather that because of his or her handicap the infant's life has such diminished value that the child *should* not live.

This difference in the treatment of handicapped and non-handicapped children directly reflects the physician's judgment that the life of the handicapped infant is of significantly less value than is the life of the non-handicapped infant. Perhaps the bias and devaluation inherent in seriously presenting the no-treatment option would be clearer if the decision were based on race or sex (other permanent physical characteristics). If physicians in a neonatal intensive care unit, in cases where clearly beneficial treatment was safely available, routinely and seriously presented the no-treatment alternative to parents of black infants but not to parents of white infants, would there be any question of inherent and unlawful bias? Would it suffice to argue that, because of a higher incidence of poverty among black families, such a differentiation in the presentation of treatment alternatives was justified either because of the potential economic burden of another child on the family or because the quality of the child's future life, as measured from the physician's sociological viewpoint, might well be significantly lower because of the child's race? The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research points out "that it is all too easy to undervalue the lives of handicapped infants" [4] and criticizes the presentation of the no-treatment

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Decision-Making for the Treatment of Myelomeningocele 72 Pediatrics 450, 452, 453, 456 (1983). *See also* Brief of *Amicus Curiae* Carlton Johnson.

[4] *Foregoing Life Sustaining Treatment,* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and

alternative by physicians where clearly beneficial treatment is available:

> . . . parents should be able to choose among alternative treatments with similarly beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved.[5]

The President's Commission goes on to urge that handicapped infants be treated "no less vigorously than older children with similar handicaps would be treated." [6]

Not all medical decisions to withhold treatment from a handicapped infant are based on different assumptions regarding the value of the infant's life. The pivotal question to be answered is, "If the child were not thought to be permanently disabled, would there be any hesitation in providing a particular type of treatment?" If the answer is "yes" (i.e., there would be a major question about providing the treatment under consideration even if a child were not thought to be permanently handicapped), then the treatment decision would be properly predicated on medical factors related to the infant's current physical condition rather than the infant's status as a handicapped child. However, if the answer is "no" (i.e., the issue of whether to go ahead with treatment is decided ultimately on the basis of an assumption regarding the "quality" of an infant's life after successful treatment), then the decision would appear clearly predicated upon the diminished value assigned to the life of that child. Thus a physician may legitimately decide not to recommend heart surgery

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Behavioral Research, U.S. Government Printing Office 219 (1983). For a description of a similar physician devaluation of life on the basis of race which led to the now infamous Tuskeegee syphilis study *see S.R. No. 93-381: Report to Accompany HR 7724 (P.L. 93-348)*, August 3, 1973, *reprinted in* 1974 U.S. Code Cong. and Ad. News 3642-43, 3652-59.

[5] *Id.* at 217-18.

[6] *Id.* at 219.

for a black child with Down's syndrome because it is medically contraindicated. However, if the physician decides not to recommend clearly beneficial surgery *because* the child is and will be mentally retarded, or *because* the child is and will be black, the basis of the physician's decision has shifted from a medical to a sociological one. There is no more central civil rights issue than a life and death difference in treatment based on a different and lesser valuation of a human life attributable to membership in a particular group.

B. Congress Acted in Light of the Historical Inequality of Medical Care and Treatment to Which Handicapped Children Had Been and Continue to be Subjected.

The passage of Section 504 of the Rehabilitation Act of 1973 [7] represents a deliberate decision by the Congress to correct historical inequities in the provision of medical care and treatment to handicapped children and adults. These historical inequities were often tied to a concept derived from Social Darwinism: that children born with disabilities were "unfit" and, therefore, not "deserving" of the medical care and treatment needed to survive. *Cf. City of Cleburne, Texas* v. *Cleburne Living Center*, 105 S.Ct. 3249, 3266 (1985) (Marshall, J., dissenting). Prior to the enactment of Section 504 numerous incidents in which physicians had withheld clearly beneficial treatment from infants solely on the basis of their handicap had been widely reported.[8] One early example of this type of "medical Darwinism" appeared in a story on the front page of the November 18, 1915 New York Times entitled: "*Defective Babe Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Coun-*

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[7] P.L. 93-112; 29 U.S.C. 794.

[8] *Order Relating to Protective Services, In re Baby Girl Obenauer*, (N.J. Juv. & Dom. Rel. Ct., Morris County, Dec. 22, 1970); Washington Post, October 15, 1971, p. 1 (*re* starvation of a child with Down's syndrome by physicians at Johns Hopkins University Hospital, Baltimore, Maryland); *see also* S. Herr, *Rights and Advocacy for Retarded People*, Chapter 23 (1983).

try's Good." [9] The withholding of beneficial medical treatment was, of course, only one of a wide variety of dehumanizing and destructive practices to which handicapped children and adults were routinely subjected.[10] During the early decades of this century, the states actively enlisted the assistance of physicians and other health workers in these practices. Physicians, social workers, and other professionals were required by law in some states to report to the government all persons "believed by them to be feeble minded".[11] Other states made it "one of the special duties of every health officer and of every public health nurse to institute proceedings to secure the proper segregation and custody of feeble-minded persons." [12] Those states with no formal reporting or registration requirement at least officially encouraged health care professionals to identify disabled children who were to be removed from the family and placed into an institution if their parents "either neglect[ed] or refuse[d] to do so." [13]

During the last decade, many physicians charged with the care and best interests of handicapped newborn infants have continued actively and openly to advocate the application of non-medical criteria to infants in order to justify withdrawing needed and clearly beneficial medical treatment. For example, a 1977 national survey of

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[9] New York Times, November 18, 1915, p. 1.

[10] *Cleburne*, 105 S.Ct. at 3266 (concurring opinion); *see also* on history of proposals to extinguish the mentally retarded as a group; *see also* S. Herr, *supra* note 8 at 23. The legislative history of Section 504 (and its related enactments) and the historical background against which Section 504 was enacted is more fully addressed in the Brief of *Amici Curiae* American Coalition of Citizens with Disabilities, *et al.*

[11] 1931 S.D. Sess. Laws 200, ch. 153, § 3(b), (c); *see also* 1917 Or. Laws 739, 740, ch. 354, §§ 1, 5.

[12] 1918 Ky. Acts 171, ch. 54, § 30; *accord*, 1919 Tenn. Pub. Acts 561, ch. 150, § 5.

[13] 1920 Miss. Laws 294, ch. 210, § 17; 1919 Tenn. Pub. Acts 564, ch. 150, § 4.

pediatricians and pediatric surgeons reported that "potential quality-of-life" was the most important criterion and "possible adverse effects to the family", the second most important criterion used to justify such decisions.[14] While much of this discussion has been couched in both "ethical" and "scientific" terminology, it has often revealed an underlying hostility toward the handicapped infant patient. One recent article by the former head of the Department of General Surgery of the Cleveland Clinic stated that "no child with Down's syndrome ever grew up to be self-sustaining" and suggested that "if the parents still want to rear their child, that should be their decision, but there should be no support from the community or the State." [15] A 1983 editorial in a prominent medical publication stated that "with luck" a Down's syndrome child with esophogeal or duodenal blockage (like Bloomington's Infant Doe) "can be trained to the point of being a happy family pet." [16] Numerous articles appearing in prominent medical publications openly advocate the withdrawal of beneficial medical treatment from handicapped infants on the basis of a wide variety of non-medical criteria, all linked directly to the presence (or anticipated presence) of a permanent handicap.[17]

Most of these articles have invariably sought to justify the withholding of clearly beneficial medical treatment

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[14] Shaw, Randolph & Maynard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 588 (1977).

[15] Dr. George Crile, *The Right to Life*, Medical Tribune December 19, 1984.

[16] Ravitch, *Big Brother Comes to the Nursery*, Surgical Rounds June 1983 at 10.

[17] *See* Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 New Eng. J. Med. 890 (1973); Angell, *Handicapped Children: Baby Doe and Uncle Sam*, 309 New Eng. J. Med. 659, 660 (1983); Todres, Krans, Howell & Shannon, *Pediatricians Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197, 198 (1977); Affleck, *Physicians' Attitudes Toward Discretionary Medical Treatment of Down's Syndrome Infants*, 18 Mental Retardation 79-81 (1980).

from handicapped infant patients on the basis of either or both of the following non-medical rationales: (1) on a cost/benefit basis society would be better off without the infant, or (2) the burdens which the infant would impose on the family are greater than any benefits to be derived. The value-to-society rationale is predicated on the assumption that only those handicapped infants who are fittest in terms of productivity and economic contribution should live. Those relying on this rationale consistently underestimate the developmental potential and employability of handicapped persons and ignore the substantial and valuable personal and economic contributions of handicapped children and adults to their families and communities.[18]

The second rationale attempts to assess the benefits and burdens of an infant's life on the infant's family. A 1980 summary of four recent surveys of physician attitudes reported that physicians primarily justified no-treatment preferences on the basis of social criteria that particularly relate to the potential for family acceptance and the integration of the child.[19] Not only does the burden-on-the-family rationale confuse the interests of the infant with the interests of the parents, it is also based on the assumption that, in general, parents, siblings, families and communities cannot cope with or adequately support the existence of a handicapped child. Most importantly, this rationale ignores the capacity of family members to grow and to love, ignores the fact that the emotional benefits to the family may well be far more important than any physical demands of caretaking,[20] and overlooks the enormous efforts and accomplishments of parents, so many of whom have unselfishly provided nurturing and support.

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[18] Walker, Feldman, Vohr & Oh, *Cost Benefit Analysis of Neo-Natal Intensive Care for Infants Weighing Less Than 1000 Grams at Birth*, 74 Pediatrics 23 (1984); *see also* Brief of *Amici Curiae* American Association on Mental Deficiency, *et al.*

[19] Affleck, *supra* note 17; *see supra* note 14.

[20] Turnbull & Turnbull, *Parents Speak Out* (2nd ed. 1985).

The National Conference of Catholic Bishops and the American Jewish Congress in a recent Joint Statement rejected both the value-to-society and burden-on-the-family rationales in concluding that an assessment of a child's best interest should not "include the possibility of negative judgments about the value of handicapped children's lives." [21] In sum, both of these rationales represent a serious assault on the traditional medical standard of treatment in the best interests of the patient. This dangerous tendency toward the introduction of sociological factors has been addressed directly by the Canadian Psychiatric Association:

> "We are also uncomfortably aware that it is all too easy to slip into 'doublethink' in this complex area of moral decision making as we exercise our medical responsibility. Our minds can easily move from the goodly desire (held we hope by all physicians) for a rich, full and satisfying life for everyone; to the recognition that, as we perceive their present situation to be, these children may never enjoy such a life; to the latter becoming the reason for our countenancing or even inducing their death. The role of medicine is to help make the quality of life the best possible for all; rather than to cut short the life of humans with various defects—regardless of the degree or type of their deficiency." [22]

C. The Legislative History Surrounding the Enactment of Section 504 Demonstrates that Congress Intended to Broadly Prohibit Unequal Treatment in the Provision of Medical Care and Treatment.

At issue before this Court in the instant case is not whether routine government oversight of medical decision-

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[21] *Principles on Treatment of Handicapped Newborns*, July 25, 1985); *See also Wyatt* v. *Aderholt*, 503 F.2d 1305, 1312 (5th Cir. 1974) with respect to the rejection of a similar argument advanced in connection with the civil commitment of mentally disabled persons.

[22] Beck, *On Withholding Treatment.* A Working Paper for the Professional Standard and Practice Council of the Canadian Psychiatric Association (1975).

making is constitutionally required, but rather whether Congress intended to extend the same civil rights protections applicable to 35 million disabled Americans to a group of infants whose lives are directly at risk because of adverse sociological judgments made by health care providers on the basis of the infant's future status (or assumed future status) as a disabled child and adult. Congress, patterning Section 504 after Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000(d), clearly intended to broadly prohibit discrimination by recipients of Federal funds in all of the activities benefitting from Federal financial assistance.[23]

The legislative history of Title VI demonstrates that Congress clearly intended that there be an "assurance that hospitals financed by Federal money would not deny adequate care to Negroes," 110 Cong. Rec. 1519 (1964) (remarks of Rep. Celler, the prime sponsor of Title VI in the House), and the final regulation implementing Title VI has for over twenty years prohibited discrimination on the basis of race, color or national origin in the operation of health care facilities receiving funds under a wide array of Federal health care programs.[24] Since that time, hospitals have been required to agree to assurances of compliance relating directly to the nonexclusionary treatment of "individuals as . . . patients," [25] and have been prohibited from discrimination on the basis of race, color and national origin both in the selection or determination of eligibility of individuals to receive "health services, and in the provision of such services." [26] Thus, civil rights obligations that bear upon the provision of medical care were at the time of passage of Section 504 neither new nor secret.

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[23] *See Alexander* v. *Choate*, 105 S.Ct. 712, 718 n.13 (1985); *Community Television of Southern California* v. *Gottfried*, 459 U.S. 509 (1983).

[24] 45 C.F.R. 80.

[25] 45 C.F.R. 80.4(d)(2).

[26] 45 C.F.R. 80.5(a); *see also* Brief of Petitioner.

The clear and unrestricted language of the statute and over nine years of experience in applying parallel provisions of Title VI forcefully argue that the intent of Section 504 was to reach the provision of Federally assisted medical care and treatment to handicapped children and adults. A contrary reading would in Judge Winter's words deprive handicapped persons "of a fairly won political victory" and "expose them to the possibility of future decisions excluding other services from Section 504. . . ." *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d at 162-63 (Winter, J., dissenting).

Along with the plain language of the statute, legislative history supplies the primary guide to the construction of Section 504. As this Court recently observed:

> "Given the lack of debate devoted to § 504 in either the House or Senate when the Rehabilitation Act was passed in 1973, the intent with which Congressman Vanik and Senator Humphrey crafted the predecessor to 504 is a primary signpost on the road toward interpreting the legislative history of § 504." *Alexander* v. *Choate*, 105 S.Ct. at 718 n.13 (1985).

The legislative history surrounding the enactment of Section 504 convincingly demonstrates that Congress was determined to reverse the historical inequities in medical care and treatment which were an important part of that history.

Congressman Vanik, in introducing the original handicap non-discrimination legislation on December 9, 1971,[27] stated "Mr. Speaker, the treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights," and immediately singled

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[27] The handicap non-discrimination legislation addressed by both Representative Vanik and Senator Humphrey was subsequently reintroduced by these sponsors and enacted as Section 504. H.R. 14033, 92d Cong., 2d Sess., 118 Cong. Rec. 9712 (1972); S. 3044, 118 Cong. Rec. 525-26 (1972).

out the "100,000 babies [who] are born with defects" annually, among the "masses of the handicapped [who] live and struggle among us, often shunted aside, hidden and ignored. How have we as a nation treated these fellow citizens?" 117 Cong. Rec. at 45974. Noting that much of what happens to handicapped people is "hidden" from the public, behind closed doors, Mr. Vanik described instances of "confinement without treatment," "brutality," and "unexplained deaths," and concluded that, with the enactment of Section 504, Congress would "no longer tolerate the invisibility of the handicapped in America." *Id.* One month later, on the floor of the United States Senate, Senator Humphrey stated that children, youth and adults with mental and physical handicaps "have the right to live" and "to know the dignity to which every human being is entitled." 118 Cong. Rec. 525 (1972). In the view of Senator Humphrey, Section 504 was designed to insure, among other equality guarantees, the "right to health," which he said was "fundamental." *Id.*

Congress was well-aware that physicians and other professional service providers often devalued the lives of handicapped children. Describing the "categories of people who would be directly affected—children who are mentally retarded, physically handicapped"—Senator Humphrey referred to the "disturbing viewpoint that these people are not only forgotten but perhaps expendable." *Id.* Senator Humphrey inserted in the Congressional Record a series of articles which contained stinging criticisms of physicians, psychologists and other professionals who seriously devalued the developmental potential and, indeed, the very lives of handicapped children and which documented the experience of parents who were told by pediatricans that their children's lives would be worthless. 118 Cong. Rec. 9499, 9500. One of these articles documented the experiences of parents who "spoke angrily about pediatricians and purported experts in the field of retardation—the professionals who know pathetically little about the unused potential of retarded children and

who continually discourage and delude parents. . . ." One of these parents stated that "there was so much willingness to eliminate the child, because they did not consider him a productive member of society. . . ." The article went on to conclude that parents share a "deep anger" at a "system which regularly has written off certain categories of handicapped children, their children, as hopeless." 118 Cong. Rec. at 9500.

In fact, Congress intended to allow no children to be "written off" as "hopeless." The legislative history surrounding the passage of Section 504 also demonstrates the express intent of Congress to include not only mildly or moderately disabled persons but also persons with severe disabilities within its coverage. 117 Cong. Rec. 45974 (1971); 118 Cong. Rec. 526 (1972). "[T]he 'expendables,'" as Senator Humphrey described them, 118 Cong. Rec. at 9495, were identified as the primary intended beneficiaries of Section 504. The legislative history also clearly includes infants and children as part of the protected class. Congressman Vanik specifically mentioned "babies . . . born with defects" as part of the group of handicapped persons to be aided by the statute (117 Cong. Rec. at 45974) and Senator Humphrey describes the sweep of the statute as one that addresses "handicapped children, youth and adults who suffer the profound indignity and despair of isolation, discrimination and maltreatment." 118 Cong. Rec. 9497-98.

In sum, when it enacted Section 504, Congress, aware of both the long and well-documented history of discrimination by medical professionals against children and adults with disabilities, clearly intended to prevent such discrimination from continuing in Federally assisted programs. Both the explicit and unrestricted language of the statute and the legislative history surrounding its passage overwhelmingly support the applicability of Section 504 to physicians and health care providers receiving Federal funds who withhold medically indicated treatment from infants solely on the basis of their handicap. If Congress

did not intend that Section 504 be construed in this manner, Congress could most certainly have fashioned an explicit exemption at the time of the enactment or at any time thereafter, including during the consideration last year of complementary provisions contained in the Child Abuse Amendments of 1984.[28]

II. DECISIONS TO WITHHOLD BENEFICIAL MEDICAL TREATMENT FROM INFANTS ON THE BASIS OF THEIR HANDICAP ARE SUGGESTED TO PARENTS BY PHYSICIANS.

A. Physicians Directly Suggest No-Treatment Decisions to Parents of Handicapped Infants.

Decisions to withhold beneficial medical treatment from handicapped infants are, in fact, frequently made by physicians and other health care providers who receive substantial amounts of Federal financial assistance. The tendency of some biased physicians to suggest their own sociological judgments to parents is well documented. The President's Commission reported that some physicians actually make decisions to withhold treatment and others manipulate the situation to ensure that parents will accept their "recommendation." [29] It reported further, that "parents may be excluded from the decisions entirely or presented with a narrower range of choices than is appropriate" and concluded that, as a result of these actions by physicians, "the child loses the protection of its surrogates." [30] If the responsible physician believes that death (i.e., withholding of beneficial treatment) is preferable to life, the physician can and often does present the options to parents in a manner which results in the direct

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[28] *See* Section 127(a) of The Child Abuse Prevention and Treatment Act and Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1984 (P.L. 98-457); *see also* Brief of *Amici Curiae* Orrin G. Hatch and Austin J. Murphy.

[29] President's Commission, *supra* note 4 at 210-11.

[30] *Id.* at 211.

imposition of the physician's judgment.[31] Physicians responding to survey questions regarding "acquiescence in parents' decisions" commented that physicians are always either directly involved in forming the decision with the parents or are in a position of directly influencing the decisions parents make through the presentation of the treatment/no-treatment question.[32] During a five year experiment 24 infants with spina bifida were denied life-saving treatment by a team of medical professionals, who, after applying a "quality-of-life" scheme, informed the parents that "we do not consider them obligated to have the baby treated." [33]

In 1981 another prominent neonatologist reported that it might take physicians seeking to instill a "death wish" in parents of handicapped infants as long as three days to succeed in breaking down their resistance.[34] The frequency with which these judgments are likely to be recommended to parents is revealed by a 1977 survey of Massachusetts pediatricians which disclosed that 51% believed that a child with Down's syndrome and duodenal atresia (blockage) should not receive surgery and 67% of the pediatricians would recommend no surgery for a child with severe myelomeningocele (spina bifida).[35] A 1980 summary of four major surveys of physician attitudes reported that social variables are the critical perceived determinants of the preference to withhold treatment.[36]

The role of the physician as described in these studies is hardly that of an independent or neutral fact finder. The

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[31] Duff & Campbell, *supra* note 17; Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'*, 167 Pediatrics 315 (1981).

[32] Shaw *et al.*, *supra* note 14 at 590.

[33] Gross *et al.*, *supra* note 3 at 452; *see also* Brief of *Amicus Curiae* Carlton Johnson.

[34] Duff, *supra* note 31 at 315.

[35] Todres, *et al.*, *supra* note 17 at 197-98.

[36] Affleck, *supra* note 17 at 80.

physician is obviously directly involved in the decision-making process and brings to it whatever knowledge, bias or stereotypes he or she possesses. At best, the physician seeks to play the role of a compassionate helper; at worst the physician may seek to impose a "death wish" or gain ratification of a no-treatment decision based on a sociological formula of which the parent is not even aware.

B. The Circumstances Surrounding the Presentation of No-Treatment Decisions Raise Serious Doubts Concerning the Quality of Informed Consent.

Parental consent to (or acquiescence in) a decision to deny beneficial treatment to a handicapped infant (i.e., the simultaneous waiver of a right to treatment and consent to the plan of non-treatment), if it is to be regarded as legally sufficient, must be free of "undue influence." [37] Certainly, the circumstances surrounding the presentation of no-treatment decisions by physicians to parents present a classic opportunity for the exertion of "undue influence." [38] The relationship between the physician and the parents, is one which has as its foundation the theory that the former is learned, skilled and experienced in those subjects about which the latter ordinarily know little or nothing.[39] Despite the vital importance of both the life and health of the child to the parent, the parent must necessarily place great reliance, faith, and confidence in the professional word, advice, and acts of the physician or other health care provider.[40] *Cf. Parham*

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[37] *Ralston* v. *Turpin*, 129 U.S. 663, 670 (1889); *Harding* v. *Handy*, 24 U.S. 11 Wheat. 103, 125 (1826).

[38] *Hummel* v. *State*, 210 Ark. 471, 196 SW 2d 594 (1946); *Adams* v. *Ison*, 248 SW 2d 791 (Ky. 1952); Annot., 50 A.L.R. 3d 918, 920 (1973); *see also* Beck, *supra* note 22 at 7.

[39] *Id.*

[40] *Id.*; *Campbell* v. *Oliva*, 424 F.2d 1244, 1250 (6th Cir. 1970).

v. *J.R.*, 442 U.S. 584, 632 (1979) (Brennan, J., concurring and dissenting) ("even well-meaning parents lack the expertise necessary to evaluate the relative advantages and disadvantages of [medical] treatment").

In light of the basic nature of the physician/patient relationship, the additional presence of one or more factors which occur frequently in the context of no-treatment "recommendations" or "alternatives" presented to parents by physicians strongly suggests that sufficient evidence of "undue influence" may be present to raise serious doubts with respect to the voluntariness of any consent given by the parent. These factors include lack of pertinent information, vulnerability of the parents' mental and emotional state, and the degree to which the physician exerting influence is directly involved in effectuating the resulting decision.[41]

Parents faced with the birth of a child with an unanticipated handicapping condition are rarely provided with accurate information related to both the current medical condition of the infant and the developmental potential and capabilities which can reasonably be predicted. What the parents require is specific, clearly transmitted, honest information about the child, implications for the future and knowledge of what concrete actions they can take to assist the infant's growth and development.[42] Often, in fact, comparatively little medically reliable information is available at or near birth with respect to the future growth and developmental potential of most handicapped infants.[43] The President's Commis-

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[41] *Ralston* v. *Turpin*, *supra* note 37 at 670; *Ostertag* v. *Donovan*, 65 NM 6, 331 P.2d 355 (1958); *Davies* v. *Toms*, 75 S.D. 273, 63 NW 2d 406 (1954); *Verner* v. *Mosely*, 221 Ala. 36, 127 SO 527 (1929); *see also In re Interest of Perry*, 31 Wash. App. 268, 641 P.2d 178 (1982).

[42] Mathbery & Vernick, *Parents of the Mentally Retarded Child: Emotionally Overwhelmed or Informationally Deprived*, 74 J. Pediatrics 953, 954 (1969).

[43] President's Commission, *supra* note 4 at 216, 221 and 228.

sion reports that parents who "are likely to be poorly informed about long-term prospects for the child, be subject to financial exigencies, and be worried about the effects on siblings and the family as a whole receive outdated or incomplete information from their physicians which limits their capacity to act as surrogate decision makers" and describes as a serious shortcoming in current decision-making about seriously ill newborns the fact that "appropriate information may not be communicated to all those involved in the decision." [44] As the Commission notes, when parents are provided information about Down's syndrome and a chance "to hear both points of view," including the availability of excellent adoptive homes, the decision changes.[45]

Studies have revealed that information provided to parents by physicians may be constrained by the physician's judgments or views concerning the social class and race/ethnicity of the infant's family, the perceived emotional stability of the parents, and the physican's lack of accurate information regarding the availability of support services to assist handicapped infants and their parents.[46] The lack of knowledge of pediatricians about handicapping conditions has been both reported to the American Academy of Pediatrics and identified by it as one of the "under-emphasized areas in pediatric residencies" and as a subject "in which education content is inadequate." [47] Indeed, studies have even re-

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[44] *Id.* at 209, 211 and 223.

[45] *Id.* at 223, Testimony of Dr. Norman Fost.

[46] McDonald, Carson, Palmer & Slay, *Physicians Diagnostic Information to Parents of Handicapped Neonates*, 20 Mental Retardation 12, 13 (1982); Kelly & Menalascino, *Physicians' Awareness and Attitudes Toward the Mentally Retarded*, 13 Mental Retardation 10 (1975); Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983).

[47] American Academy of Pediatrics, *Pediatric Education: A Report by the Task Force on Pediatric Education* (1978).

ported that the medical prognosis provided by physicians to parents consistently underestimates the infant's actual chances of survival.[48]

Compounding the lack of information available to parents is the vulnerability of the parents' mental and emotional state. After the birth of a sick and handicapped infant, families are often in "a severe psychological crisis" in which they are foreclosed, as a result of psychological and emotional trauma that generally surrounds the birth of a handicapped infant, from either assimilating properly the information which is provided about the infant's condition or exercising clear and rational judgment concerning a no-treatment decision presented by a physician.[49] In addition, time pressures, often artificial and unnecessary,[50] imposed on parents to consent or acquiesce in the physician's recommendation affect both the capacity of the parents for rational judgment and the quality of the information upon which to base a judgment. This, of course, is the same period of time during which the mother is recuperating from the physical demands of childbirth and may be receiving medication or other medical treatment. The President's Commission has cautioned against "undue haste in decision-making" and observed that "[t]he longer some of the babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals

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[48] Clyman, Sondeman, Ballard & Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counseling Process*, 63 Pediatrics 719 (1979).

[49] Scanlon, *Who Provides Intensive Emotional Care in the NICO*, Professional Nursing (November-December, 1978) at 18; Strong, *The Neonatologist's Duty to Patient and Parents*, 14 Hastings Center Rep. 10, 11 (August 1984); Darling, *Parents, Physicians and Spina Bifida*, 7 Hastings Center Rep. 10, 11 (August 1977); Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 Pediatrics 32 (1981).

[50] Charney, Weeler & Sutton, *Management of the Newborn with Myelomeningocele: Time for a Decisionmaking Process*, 75 Pediatrics 58-74 (1985).

can be on whether further treatment is warranted or futile." [51] Both research and experience have shown that, after a period of time, parents' attitudes towards the infant they might once have hoped would die may well change, as a relationship of love and affection is allowed to develop.[52] In fact, one medical commentator, concerned that time and the opportunity for bonding it creates may well cause parents to make a "selfish" decision to save the infant's life, actually recommends that parents not be encouraged to nurture their newborn infant.[53]

In sum, because parents often receive biased, incomplete and inadequate information, and are asked to make decisions at a time of psychological and emotional crisis without adequate support, and under time pressures which are often neither necessary nor conducive to informed and reasoned judgment, experience and reality demonstrate a very strong opportunity for the imposition of undue influence by physicians and other health care providers.

The inherent authority and presumed medical/technical knowledge of pediatricians and pediatric surgeons creates a disposition in a significant number of these physicians to exert influence over decisions to withhold medically indicated treatment. In these instances "what passes today for disclosure and consent in physician-patient interactions is largely an unwitting attempt by physicians to shape the disclosure process so that patients will comply with their recommendations" [54] despite the underlying as-

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[51] President's Commission, *supra* note 4 at 216, 221 and 228.

[52] Darling, *supra* note 49. It should also be noted that the parents of Baby Jane Doe, in fact, changed their minds after several months and decided to provide life-sustaining care and treatment.

[53] Pauli & Cassell, *Nurturing a Defective Newborn—Commentary*, 8 Hastings Center Rep. 13, 14 (February 1978).

[54] Katz, *Informed Consent—A Fairy Tale? Law's Vision*, 39 U. Pitt. L. Rev. 137, 142 (1977).

sumption of the physician/patient relationship which is that the physician seeks to prevent illness, to promote healing, to reduce suffering and to save life.[55] As the Canadian Psychiatric Association has observed:

> "Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted. Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death—when it accepts the death of an individual as a means of solving the problems of either the family or of society." [56]

The experience of Amici, as parents of handicapped children (discussed at length on pages 18 through 24 above) demonstrates that the strong preference for non-treatment of handicapped infants held by a significant number of health care providers has in many instances unduly influenced the normal resolve of parents to preserve the health, welfare and physical well-being of their infants and children. In this regard the President's Commission reports that actions have and can be taken to withhold medically indicated treatment from handicapped infants "without the informed approval of parents or surrogates" and observes that "parents may be excluded from the decisions entirely or presented with a narrower range of choices than is appropriate." [57]

As parents of both handicapped children and their non-handicapped brothers and sisters, Amici recognize that our moral and philosophical heritage strongly suggests that a true parent always chooses life for his child and never willingly accepts the loss of a child. This, after all, was the way that King Solomon determined the true

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[55] *See supra* note 22 at 2.

[56] *Id.* at 3.

[57] President's Commission, *supra* note 4 at 209 and 211.

mother between the rival claimants—that the true mother would never countenance the death of her child, no matter how much suffering its continued life would bring to her. It is precisely the ability of some biased physicians to impose sociological judgments on parents which are sharply at odds with traditional concepts of parental caretaking that demonstrates that "undue influence" has seriously impaired the quality of parental consent.[58]

C. The Unreliability of the General Expectation that Parents Will Act in the Best Interests of Their Children Supports the Applicability of Section 504.

This Court in *Parham* v. *J.R.*, 442 U.S. 584 (1978) identified several assumptions that underlie the general expectation that parents will act in the "best interests" of their children: (1) "parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions," (2) parents have "natural bonds of affection" towards their children, and (3) parents, faced with treatment decisions in situations of *bona fide* medical uncertainty, will make such decisions after receiving independent medical advice from physicians as to the course of treatment which will best meet the child's treatment needs.[59] In addition, this Court pointed out that certain other factors, including both a concern that raising questions about the motives underlying parental decisions might seriously disturb the ongoing coherence of the family unit (and by doing so adversely affect the future treatment of the child) and a reliance on the protection afforded by subsequent professional review of the treatment decision,[60] support the need for lessened governmental scrutiny.

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[58] *See* R. Burt, *Refusing Care* in The Handicapped Newborn in American Society (J. Bopp ed. 1986) (in publication). A copy of this document has been placed on file with the Clerk of the Court.

[59] *Parham* v. *J.R.*, 442 U.S. 584, 602, 604, 607-10, 613 (1978).

[60] *Id.* at 610, 617 and 619.

As is discussed at length on pages 18 through 26 of this brief, in fact, none of the usually valid assumptions identified by this Court as underlying this general decision to allow governmental deference to parental authority proves reliable in the case of parents forced to consider no-treatment decisions for their handicapped children. First, experience demonstrates that the "maturity, experience and capacity for judgment" normally anticipated from parents is often absent in these decisions, as parents, deprived of pertinent information, are forced, during a period of psychological crisis, to make hurried decisions to acquiesce in sociological judgments presented to parents as the "recommendation" of a significant number of health care providers trusted by the parent to "heal" and "save life." Second, the "natural bonds of affection" which normally lead parents to act in the best interests of their children have usually not yet formed with respect to the handicapped infant. Third, the introduction of sociological judgments by physicians distorts the normal role of parental decision-making in a context of *bona fide* medical uncertainty. Here, physicians ask parents to abandon their natural role as protectors of their children and undertake to decide between life and death. Instead of the neutral fact-finder envisioned in *Parham*, the physician may well be the architect of the problem rather than a contributor to its solution. Finally, the assumptions in *Parham* based on concerns about the future environment of the child and the protection afforded by subsequent professional review or intervention by family and friends prove illusory where the life of the child is forfeit.[61] In the instant case, both "experience and reality" overwhelmingly demonstrate the unreliability of the assumption that parents (or physicians acting through parents) will act in the "best interests" of the infant.

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[61] *Cf. The Guardianship of Becker*, 188 California Reporter, 781 (App. 1983); Herr, *The Philip Becker Case Resolved: A Chance for Habilitation*, 22 Mental Retardation 30 (1984).

While the Constitutional standard for required governmental action is not at issue in the instant case, the inapplicability of these basic assumptions to decisions to withhold treatment from handicapped children provides support both to the intent of Congress to regulate such treatment decisions within the framework of Section 504 and to the Secretary's consistent construction of the statute to authorize such regulation. This Court concluded in *Prince* v. *Massachusetts*, 321 U.S. 158 (1944) that "[P]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances to make martyrs of their children . . . ." *Id.* at 170. Congress and the Secretary surely may conclude that physicians and other health care providers are similarly barred from making martyrs of infants because of their handicap.

III. THE LANGUAGE OF BOTH SECTION 504 AND ITS 1977 IMPLEMENTING REGULATION CLEARLY PROHIBIT NO-TREATMENT DECISIONS MADE ON THE BASIS OF HANDICAP.

The plain language of Section 504 prohibits the denial of the benefits of any Federally assisted program to any person solely on the basis of that person's handicap. The legislative history of the statute demonstrates the intent of Congress to reach all aspects of discrimination against handicapped children and adults which occur in the provision of medical and treatment, including the "unexplained deaths" referred to by Congressman Vanik.[62] The "legislative heritage" of Section 504 as a civil rights statute, which, as understood by both the Legislative and Executive Branches, adopted the analogy of handicap to race and prohibited the use of handicap as the sole ground to differentiate between individuals, is set forth compellingly in Judge Winter's dissenting opinion below.[63]

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[62] 117 Cong. Rec. at 45974.

[63] *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 162-63 (2d Cir. 1984) (Winter, J., dissenting).

The 1977 Departmental Regulation implementing Section 504, 45 C.F.R. 84, defines a qualified handicapped person, in the context of health care, to be one who meets the essential eligibility requirements for the service—i.e., need for particular beneficial medical treatment and care —and has, since 1977, prohibited disparate treatment of handicapped infants and their parents within such programs except as necessary to ensure that the services are equally effective.[64] Moreover, the regulation has required that such programs avoid any methods of administration, that would defeat or impair the objective of the treatment program i.e., improved health and welfare of the patient.[65] Last year, again with the strong involvement of numerous national parent organizations, Congress acted to clearly define the withholding of medically indicated treatment for a handicapped infant (under most circumstances) as medical neglect.[66] Certainly, medical neglect is harm. To the extent that it occurs on the basis of handicap in a program receiving Federal financial assistance, it is the type of harm based on discrimination which is prohibited by Section 504.

Amici, as parents of both handicapped and non-handicapped children, are well aware of the fact that those who operate hospitals or other health care facilities would never tolerate withholding essential services from non-handicapped children. Indeed, absent the bias directed against handicapped persons, no one would suggest that it would be appropriate to do so for *anyone*. Thus, if handicapped children were treated like non-handicapped children, beneficial medical services would never be withheld. As the legislative history of the statute clearly reveals, if Congress intended to prohibit anything under Section 504, it intended to forbid intentional harm di-

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[64] 45 C.F.R. 84.3(k)(4), 84.4(b)(1)(iv).

[65] 45 C.F.R. 84.4(b)(4).

[66] *See* Brief of *Amici Curiae* Orrin G. Hatch and Austin J. Murphy.

rected against handicapped children solely on the basis of their handicap by physicians and hospitals receiving Federal funds.

Thousands of parents of handicapped children led the hard-fought and long-pursued struggle to secure through the passage of Section 504 of the Rehabilitation Act of 1973 a statutory assertion of the equal value which must be afforded to the life of each handicapped child. A decision by this Court that Section 504 does not reach handicapped infants at risk of death because of decisions to withhold treatment made on the basis of their handicap would deprive handicapped children and their parents, in Judge Winter's words, "of a fairly won political victory" and expose them "to the possibility of future decisions excluding other services from Section 504."[67] If, as this Court has concluded in *Cleburne*, Section 504 belies the historical antipathy and prejudice toward mentally retarded and other disabled persons,[68] then surely, it must protect their lives from sociological judgments made by biased health care providers and paid for from the Federal treasury.

CONCLUSION

For the reasons set forth above, Amici urge this Court to reverse the judgment of the Court of Appeals for the Second Circuit.

Respectfully submitted,

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[67] *See supra* note 63.

[68] *Cleburne*, 105 S.Ct. at 3256.

APPENDICES

APPENDIX A

CANADIAN PSYCHIATRIC ASSOCIATION
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[SEAL]

THE CANADIAN PSYCHIATRIC ASSOCIATION

POSITION PAPER

ON WITHHOLDING TREATMENT

2a

ON WITHHOLDING TREATMENT

A Working Paper

for

The Professional Standards and Practice Council

of

The Canadian Psychiatric Association

prepared by
M. N. Beck, M.D.
May 1978

This paper will offer a brief overview of the argument against the practice of withholding medical treatment from newborn retarded children.

The ethical issues stemming from this practice are most pointedly drawn by withholding repair of atresia of the duodenum in infants with Down's syndrome—"an easily correctible lesion" (1).

Similar principles are involved, but with more complex factors to be evaluated in terms of diagnosis and prognosis in cases of meningomyelocoele.

The Present Scene

In considering this practice we do not discuss a theoretical issue, but we deal with facts in clinical medicine in Canada today.

50 children with Down's syndrome and duodenal atresia were attended at the Sick Children's Hospital in Toronto over twenty years, of these, 27 were allowed to die (2).

This increasingly common act in medical practice is being vigorously promoted by able and influential advocates within our profession and within our society at large.

Withholding treatment from mongoloid children was first openly advocated as a valid option to Canadian medicine by Frank Guttman, M.D., F.R.C.S. in his article "On Withholding Treatment" in the Canadian Medical Association Journal of September 21, 1974 (1). Since then this topic has been subject to much discussion in the correspondence section of this Journal (3, 4).

Cooperman discussing meningomyelocoele in an editorial in the C.M.A.J. favors withholding treatment (5). In the New England Journal of Medicine April 1976 John Lachs, Ph.D. discussing the same topic commented, "the system if rightly conceived would not condone murder,

for those humanely put to death would not be human beings, only human forms" (6). In this he follows the philosophical position taken by the well known American theologian Joseph Fletcher (7, 8).

This practice has found professional support from such distinguished Canadian physicians as Dr. Clinton Stephens, Chief of General Surgery, Hospital for Sick Children, Toronto (9) and Dr. Colin Ferguson, Surgeon in Chief, Children's Hospital, Winnipeg (10) in their statements in the public media.

Individual instances of this practice have received wide coverage in the Canadian press (11, 12) and such reputable newspapers as the Montreal Gazette have given this practice editorial endorsement.

Battles both to permit and to enjoin this practice have been fought in Canadian and American Courts of Law (13, 14, 15).

The church is also involved. Withholding treatment was eloquently advocated in the report of the Anglican Task Force on Human Life prepared for consideration by the National Synod of the Anglican Church in Canada in August of 1977. This Task Force was headed by Dr. Lawrence Whytehead, a surgeon from Winnipeg, and had in its membership others from the medical and nursing professions. The report of this Task Force was just as eloquently condemned by the statements issued in response to it by the Canadian Association for the Mentally Retarded and other groups (16, 17).

The Professional Identity of the Physician

We recognize that many have advanced arguments for the withholding of treatment which are cogent both to themselves and to others. But we must ask, "is this the task of the physician?"

The aspiration of our profession has always been to spare no effort in our attempt to prevent illness, to promote healing, to reduce suffering and to save life.

The time-honored ethic of medicine, that a live patient is better off than a dead one and that a well person is better off than a sick one, is a simple ethic . . . but it has been an effective one.

Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted.

Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death—when it accepts the death of an individual as a means of solving the problems of either the family or of society.

In this context using terms such as "ordinary means of treatment" and extraordinary means of treatment" is irrelevant. These concepts are outside that range of attitudes which the physician can adopt without running the risk of becoming an agent of harm to his patient.

The physician must be on the side of his patient. This is his traditional role, this is his moral role, and this is his only role.

The Clinical Reality

Psychiatrists have had the privilege to become those physicians most closely acquainted with that warm hearted, effervescent, usually happy, and warmly responsive group of people our society usually calls "mongoloids." They have taught us much about the appreciation of life, and they have shown us by their example the virtue and the value of an open human spirit.

We have also become familiar in our practices with the burden that can be placed on the family by retarded

children. However; experienced child psychiatrists will agree that the person afflicted with Childhood Schizophrenia, a disease more difficult to diagnose than Down's syndrome, causes more personal distress to the patient and suffering in his family (to say nothing of frustration and despair to medical people) than do mongoloid children or children with meningomyelocoele.

We would not decry all suffering, confuse it with illness or use it to justify less than the best of medical care. Suffering, like death, is a part of life. While it is terrible to bring it about unnecessarily, people often act nobly in accepting it, and through suffering their life has been enriched (18).

The members of this Association, parents, family members and others who have lived and worked closely with the retarded and their families also know the power of retarded children to strengthen and to revitalize their family units.

Whether the family unit becomes stronger or weaker depends upon those with whom they interact, as well as upon the retarded persons themselves. Neither human frailty, nor the ability to inflict suffering on others, is limited to intellectually subnormal individuals.

The Psychiatric Scene Today

During the professional lifetimes of many of our members, we have participated in a remarkable, even astounding, series of advances in the treatment of disorders of the mind. We ought to no longer assume that disorders of the mind are incurable, irreversible or always attended by much suffering.

In the thirties we saw a substantial reduction in our mental hospital population by the successful treatment of the psychotic illnesses caused by nutritional deficiencies.

In the forties we took part in the virtual elimination of General Paresis of the Insane. Till then patients with this disorder had occupied 5% of mental hospital beds.

In the forties and fifties we have seen the scourge of Manic-Depressive Psychosis become a highly treatable illness; first by the use of electro-shock therapy, then by the use of anti-depressant drugs, and more recently by the use of the simple salt lithium carbonate.

In the mid fifties the introduction of the major tranquilizers enabled us to obtain dramatic symptomatic improvement in the large number of our patients who suffer from schizophrenia.

During these same decades refinements of the techniques of psychotherapy brought about significant progress in the treatment of the psychoneuroses.

During the sixties we observed with delight the normal development of children born with phenylketoneuria and other inborn errors of metabolism which until then had invariably produced severe mental retardation. This advance was made possible by special diets. In the same decade because of improved surgical techniques we have watched large numbers of children growing up with intelligence in the normal range who would otherwise have been profoundly retarded because of hydrocephalus.

Of all times in history, this is not the one in which to be pessimistic about the possibility that still more major breakthroughs will be made in the treatment of mental disorders. The reasonable man now has good cause to anticipate the development of a biological method of treatment to correct or to modify the effect of the genetic defect which causes Down's syndrome.

These are not the times in which we should be either starting or expanding the practice of letting mongoloid infants die.

We also face this issue of withholding treatment at the very point in Canadian history when the efforts of voluntary associations like the Canadian Association for the Mentally Retarded and The Canadian Mental Health Association, along with the efforts of professional groups such as The Canadian Medical Association, The Canadian Paediatric Association and our own Association have succeeded in diminishing that oppressive social stigma which had been the lot of persons suffering from retardation and other handicaps. Working together we have also demonstrated that with good family care and with adequate education rehabilitation and therapy, that retarded people make an invaluable contribution to the depth and the texture of the matrix of our society.

"Conventional wisdom" can no longer adequately serve as the prognostic guide in any disorder of the mind. Prognosis in mental diseases involves the assessment of a complex interrelated set of genetic, biochemical, psychological, social and cultural factors in a world where new and major therapeutic breakthroughs in all these areas of study has become a regular occurrence.

The Philosophical Dilemma

The distinguished jurist of the State of Maine who found against withholding surgery in a brain damaged infant commented that, "the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise" (16). We agree. We would also accept as valid the parallel statement, "that philosophy has no special competence in moral decision making."

We are aware that the heat involved in this issue besetting medicine arises from confrontation between persons who advocate a system of ethics centered on the "sanctity of life" on the one hand, and persons who hold a system of ethics centered on "the quality of life" on the other hand.

These value orientations weigh upon physicians in a particularly unique way. Our moral judgments, whether they be right or wrong, can exert undue influence on others because of our social role; and also because we are interacting with the members of the infant's family at a time when their lives are in acute crisis.

Sweating from the heat of this philosophical and ethical confrontation, we find helpful direction from our awareness that there is a profound distinction between maintaining life and prolonging death. Physicians can determine when death is inevitable with reasonable certainty. Merely postponing the time of death has never been accepted as good medical practice.

Our profession had incorporated this principle into its definition of good medical care long before the much heralded advances in bio-medical technology of the last few decades—which advances are now erroneously proposed as the reason for our having to rethink our ethics on the issue being discussed in this paper.

We recognize the logic in the sentiment expressed by Freeman that it is time that society, and medicine, stopped perpetuating the fiction that withholding treatment from those who will thereby continue to live, is ethically different from terminating life.

We are also uncomfortably aware that it is all too easy to slip into "doublethink" in this complex area of moral decision making as we exercise our medical responsibility. Our minds can easily move from the goodly desire (held we hope by all physicians) for a rich, full and satisfying life for everyone; to the recognition that, as we perceive their present situation to be, these children may never enjoy such a life; to the latter becoming the reason for our countenancing or even inducing their death.

The role of medicine is to help make the quality of life the best possible for all; rather than to cut short the life

of humans with various defects—regardless of the degree or type of their deficiency.

Finally, we recognize that the protection of, and provision for, the welfare of the handicapped is a highly significant yardstick of the quality of our civilization; and that as stated by Dr. David J. Roy, "when we stand before a broken child and ask what we should do or avoid doing, we also stand before ourselves and before the civilization we both reflect and shape."

Recommendations

We therefore recommend:

1. That the Canadian Psychiatric Association oppose the practice of physicians withholding treatment of any kind, from retarded persons, which would not be withheld from persons with normal intelligence.

2. That physicians constantly strive to preserve life. And that when the medical reality of merely prolonging the process of dying is not involved, that withholding treatment be considered a legal and not a medical act; and that it be carried out—if at all—only under court order.

3. That the Canadian Psychiatric Association recognizes that the parents involved in these very difficult decisions need sympathetic and understanding assistance from experts in medicine, law, ethics, and clerical counselling; and that in a unique way it is the responsibility of physicians, and especially of psychiatrists, to see to it that the parents and family are fully informed.

4. That the Canadian Psychiatric Association advise the Canadian Medical Association and relevant specialty associations of our position on this matter.

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APPENDIX B

Principles on Treatment of Handicapped Newborns

American Jewish Congress/Bishops' Committee for Pro-Life Activities

1. We agree on the sanctity of human life. Every newborn has the right to basic care: nurture, sustenance and relief from pain. In cases where parents are unable or unwilling to provide such care, our government should take all reasonable steps to do so.

2. Medical intervention is not required when such intervention is clearly futile and would do no more than briefly prolong the act of dying.

3. Handicaps, in and of themselves, do not justify withholding medical treatment when such treatment offers reasonable hope of benefit and does not impose excessive pain or other burdens on the patient.

4. When there is reasonable disagreement among medical experts concerning the risks and effectiveness of alternate treatments for a life-threatening condition, parents have the right and obligation to make conscientious and medically informed choices between alternate methods of treatment. Parents who must make such difficult choices should ask themselves what course of action seems most likely to promote their child's best interest.

5. Government ought not to intervene in medical decisions made by parents of handicapped children unless there is a preponderance of evidence that one or more of the foregoing principles is being violated.

6. Government in this country should lend its support to the continuing treatment and care of handicapped children so that parents can make decisions about treatment without undue financial pressure.

COMMENTARY ON "PRINCIPLES ON TREATMENT OF HANDICAPPED NEWBORNS"

Today's joint statement on treatment of handicapped newborns was developed at a discussion between the staffs of the National Conference of Catholic Bishops and the American Jewish Congress on May 24, 1984 and refined since then by further dialogue. Our agreement on six basic principles does not unambiguously reflect all the concerns of the Catholic or Jewish participants in this area, nor could any one statement reflect the full complexity of our respective traditions in this area, but it does represent a significant consensus on both medical ethics in general and the rights of citizens with disabilities in particular. We would like to comment briefly on each of the six principles in our statement.

(1) Respect for the inherent dignity of human life demands that basic sustenance and care be provided to handicapped infants, quite aside from medical intervention that may be necessary to correct a particular life-threatening condition. Our reference to government support for such care is intended to mean that the level of government with authority to act, whether local, state or federal, should assist handicapped children as it assists others in need.

(2) Treatment which can only briefly prolong the dying process is not morally obligatory. Taken together with (1), this corresponds to the Catholic teaching that "when inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted" (*Declaration on Euthanasia*, 1980). In dealing with dying patients, non-routine medical intervention aimed at prolonging life can also hasten the moment of death. Since Jewish teaching prohibits such hastening, parents facing such a dilemma have the right

in choosing medical treatment to choose the course of action that seems to them the most prudent.

(3) Treatment of handicapped newborns should respect the principle of non-discrimination. To use terms which are common in medical ethics: morally obligatory or "ordinary" means do not become optional or "extraordinary" merely because the patient is handicapped. Treatment decisions should take a handicap into account only when it substantially decreases the benefit or increases the burden of a particular treatment. A similar policy was expressed in a May 1982 directive for the U.S. Department of Health and Human Services, which said that an infant's handicap does not justify withholding life-sustaining treatment unless it renders that treatment "medically contraindicated."

(4) Medical procedures are rarely without risks. At times, parents must choose between alternate methods of treatment or no treatment at all. It is the right of parents to weigh risks and choose the course of action that seems to them to yield the proper risk/benefit ratio. Parental choices in such circumstances should be made in terms of what course of action will serve the child's best interest. What is best for the individual child should take precedence over any conflicting interests of parents or society. The expression "child's best interest" does not include the possibility of negative judgments about the value of handicapped children's lives.

We recognize that the phrase "best interest of the child" is not without ambiguity as a legislative standard, for the phrase could be misused to mask subjective judgments about the value of handicapped children's lives. A more complete analysis is needed to spell out the phrase "best interest" in objective terms—for example, by stating that parents should take the option that seems to have a reasonable chance of advancing the child's long-term survival—but this matter requires further study and discussion.

(5) Where parents are not denying basic care to their child, not discriminating on the basis of handicap, and not acting out of ignorance or lack of conscientious concern, their medical decisions should be respected by the law. But the appropriate agency of government should be able to investigate plausible claims that these principles have been violated; if it finds a preponderance of evidence for concluding that they have, it should act to protect the child. Our consensus statement does not discuss what the most appropriate mode of reporting or investigation might be in such cases, and does not specify a particular type of government intervention to protect children's rights.

(6) Parents often feel a pressure toward denying life-saving treatment to their handicapped children when they contemplate the cost of supportive services—or the lack of such services—for the child who survives. Increased local, state and federal assistance for these children and their families is an important ingredient in any complete solution to the problem of discrimination against handicapped newborns.

In conclusion we would like to express our satisfaction with the atmosphere of cooperation and mutual esteem in which this dialogue has been conducted. We rejoice in our common ground of concern regarding this serious contemporary problem and look forward to further discussions.

Rev. Edward M. Bryce
Director, Office of Pro-Life Activities
National Conference of Catholic Bishops

Dr. Michael Wyschogrod
Director, Institute of Jewish-Christian Relations
American Jewish Congress

July 25, 1985

APPENDIX C

Resolution Adopted by the Association for Retarded Citizens of the United States

May 1, 1982

WHEREAS, the Association for Retarded Citizens of the United States is gravely concerned that the practice of withholding medical treatment from persons—solely on one basis of a diagnosis or prognosis of mental retardation—is increasing in this country at an alarming rate;

THEREFORE BE IT RESOLVED, the Association for Retarded Citizens of the United States reaffirms the position it took in 1973 condemning such practices,

AND, FURTHERMORE, does *not* support the right of physicians to recommend *nor* the right of parents to agree to the withholding of medical treatment where the only basis for such a decision is the diagnosis or prognosis of mental retardation.

FURTHERMORE, it is the position of the Association for Retarded Citizens of the United States that counseling by a physician regarding the "quality of life" for an individual with mental retardation should never extend beyond the physician's *medical* knowledge of the condition.

BEST AVAILABLE COPY

Supreme Court, U.S.
FILED
AUG 29 1985
JOSEPH F. SPANIOL, JR.
CLERK

No. 84-1529

IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

vs.

AMERICAN HOSPITAL ASSOCIATION, et al.

Respondents.

ON A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF CARLTON JOHNSON IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

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INTEREST OF AMICUS CURIAE

Carlton Johnson, a black male infant, was born September 12, 1982. At birth, Carlton had myelomeningocele, hydrocephalus, and associated congenital anomalies. Carlton did not receive optimal medical treatment. Instead, he was subjected to a discriminatory selection process that denied him appropriate medical care — surgery, placing a shunt and, later, antibiotics and intravenous fluids. Carlton, unfortunately, did not meet the intellectual, social, economic, and other nonmedical criteria deemed necessary to provide disabled infants access to proper treatment at Oklahoma Children's Memorial Hospital. He was, therefore, denied beneficial medical treatment and transferred to a nursing care facility. Surprisingly, Carlton survived and a year later the myelomeningocele team at Oklahoma Children's Memorial Hospital reconsidered their initial recommendation for non-treatment. Carlton finally received definitive medical care in January, 1984 — a year and a half after his birth. Further evaluation is necessary to determine the degree of intellectual and physical impairment Carlton suffered as a direct result of the delay in treatment.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), is intended to prevent discrimination on the basis of handicap. When Carlton Johnson was denied access to medical treatment because of his handicaps — medical treatment that an infant without disabilities would certainly have been provided — Carlton's civil rights under Section 504 were violated.

The National Legal Center for the Medically Dependent and Disabled, Inc., a support center for the Legal Services Corporation, represents Carlton in a prospective class action litigation against individuals associated with Oklahoma Children's Memorial Hospital who selected Carlton and other disabled children for non-treatment. An allegation that Section 504 was violated by this selection

process is the crucial federal civil rights claim to be raised by Carlton and his class. If Section 504 is held not to apply to discriminatory medical practices, then Carlton will not have this remedy available. This brief is thus offered to illustrate the need for the application of Section 504 to protect infants like Carlton. All parties have consented to the filing of this brief.

SUMMARY OF ARGUMENT

A selection program that qualified some infants for life-saving medical treatment and rejected others, illustrates the compelling need for Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982) (hereinafter cited as "Section 504"), to apply to discriminatory medical practices.

This selection program, implemented by a team of health care professionals at Oklahoma Children's Memorial Hospital, a state institution, was applied to infants with a congenital disability known as myelomeningocele — an opening in the spine. The results of the program over a five year period were reported in medical literature. During this process of selection among children with treatable problems, social, economic, intellectual, and other non-medical criteria were considered before the infant was permitted full access to medical treatment. All of the twenty-four infants subjected to this selection process, and who were recommended for only "supportive care," died. The euphemism, "supportive care" entailed denial of beneficial medical treatment; it consisted of minimal comfort-care, without the use of antibiotics or sedatives. Recommendations for "supportive care" were made for about half of the infants seen, even though these children had the same chance for survival with appropriate treatment as did those infants who were deemed "worthy" of proper treatment.

The plain language of Section 504 was violated twice when these handicapped infants were denied the benefits of medical treatment: 1) when the infant who had a prognosis

for survival with a "significant" handicap was placed in a selection program instead of receiving proper treatment; 2) when an infant in the selection program was evaluated on the basis of social, economic, and intellectual criteria, as well as the degree of the child's physical disability and the economic, intellectual, and emotional resources of the family, in order to determine if the child qualified for treatment.

Carlton Johnson is a black male born with myelomeningocele. Now nearly 3 years of age, he was evaluated by the myelomeningocele team at Oklahoma Children's Memorial Hospital shortly after his birth and shortly after the time of the reported study. Carlton did not meet the social, intellectual, economic, and other nonmedical criteria necessary to qualify him for proper treatment. He was transferred, presumably to die, to an intermediate nursing care facility.

One month later, Carlton returned to Oklahoma Children's Memorial Hospital. He was critically ill, suffering from severe dehydration and an ear infection. Instead of the aggressive therapy that any nonhandicapped child would have received, Carlton was denied the benefits of laboratory tests to monitor his condition, intravenous fluids, and antibiotics. But surprisingly, Carlton improved after rehydration through oral-gastric tube feedings. His infection subsided on its own.

Carlton Johnson's rights under the plain language of Section 504 were violated twice at Oklahoma Children's Memorial Hospital. During his first admission, he was subjected to an evaluation that led to a recommendation for "supportive care" only, which discriminatorily denied him access to beneficial medical treatment. During his second admission, Carlton was deprived of appropriate treatment in a life-threatening situation — treatment that would have, without question, been provided to any nonhandicapped infant.

Section 504 must be held to apply to discriminatory

medical practices so that the federal government has the power to investigate and remedy these types of discriminatory conduct. Yet due to the injunction issued by the lower court in this case, the Department of Health and Human Services has been unable to investigate or remedy the situation at Oklahoma Children's Memorial Hospital.

While it is asserted that the final decision for "supportive care" or treatment — actually a decision between life and death — was left to the parents, parents do not have the informational and emotional resources available to them to make a competent decision immediately after the birth of their disabled child. The parents routinely relied on the expertise of the myelomeningocele team; there is no evidence that the parents are told of the nonmedical social, economic, and intellectual criteria considered in making the recommendation. The myelomeningocele team in fact made the decision, not the parents. After a decision for "supportive care" was effectuated and the child died, rights to the companionship, care, and custody of the child were lost. Thus, not only were child's rights discriminatorily denied, but parental rights were also violated.

A recent Act of Congress treats the type of discriminatory conduct evidenced by the selection process at Oklahoma Children's Memorial Hospital as child abuse. But the sole remedy the Act provides is termination of federal funds to state child neglect and abuse agencies that fail to pursue such instances of abuse. Unless Section 504 applies to discriminatory medical practices, the federal government would be compelled to continue funding such discriminatory medical treatment regimens, but be required to terminate funding to state child protection agencies that fail to pursue such instances of child abuse — an absurd and anomolous result.

The federal government must have the power to investigate and remedy allegations of discriminatory medical practices in order to protect both disabled infants and their parents; Section 504 must be available to parents and disabled children to provide them a federal remedy for

medical discrimination. Children like Carlton Johnson are in obvious need of the protection of federal civil rights law. A decision by this Court that Section 504 does not apply to discriminatory medical practices would unjustly deprive the federal government, disabled children, and their parents of this remedy.

ARGUMENT

I. INTRODUCTION

This amicus curiae brief is submitted on behalf of Carlton Johnson, a child who has been subjected to discriminatory medical treatment because of his disability, in support of the position of the United States that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), applies to discriminatory medical practices.

The compelling need for the application of Section 504 to discriminatory medical practices shall be demonstrated by description of a selection process, implemented at Oklahoma Children's Memorial Hospital, a state institution, designed to sort out infants for treatment or nontreatment based on projected intellectual status, their ability to walk, and social and economic factors. This selection process has been fully described and discussed in an article authored by several of the health care professionals who participated in it. Twenty-four disabled children subjected to this process died after they were selected for the nontreatment on the basis of criteria that clearly violate the plain language of Section 504. The personal tragedy of Carlton Johnson, who has been subjected to two separate and distinct violations of Section 504 as a patient at Oklahoma Children's Memorial Hospital, will also be described.

By holding that Section 504 does not apply to discriminatory medical practices, the Court of Appeals for the Second Circuit in *American Hospital Association v. Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984), *cert. granted*, 105 S.Ct. 3475 (1985), effectively forbade the United States

from undertaking any investigative or enforcement action to stop such blatant discriminatory conduct; it foreclosed children with disabilities or their parents from invoking the protection of Section 504 in the face of past or continuing discriminatory medical practices.

If the Second Circuit decision is affirmed by this Court, then Carlton Johnson and and other young disabled children will not have the remedies afforded by Section 504 available to them; the federal government will be impotent to intercede on behalf of these vulnerable infants even in the face of egregiously discriminatory medical practices. Such an absurd and unjust result must be rejected by this Court.

II. THE SELECTION PROCESS AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL ILLUSTRATES THE COMPELLING NECESSITY THAT SECTION 504 APPLY TO DISCRIMINATORY MEDICAL PRACTICES.

In October, 1983, a program of early selection for treatment or nontreatment of infants born with myelomeningocele was described in the medical journal *Pediatrics*. Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983) (hereinafter cited as "Gross"). The program was developed at the University of Oklahoma Health Services Center in 1977, and the report encompassed the five year period from 1977 through 1982.

During this five year period, sixty-nine infants were screened; thirty-three were recommended for "supportive care" — an euphemism for denial of beneficial medical treatment — on the basis of intellectual, social, and economic criteria. The twenty-four infants who in fact received "supportive care" all died within 189 days of birth. *Id.* at 452-53.

A. The Selection Process Discriminated Against Infants with Congenital Disabilities.

The selection process applied to infants born with myelomeningocele. A congenital disability, myelomeningocele is characterized by an opening in the spine at which a "sac" protrudes from the body of the child. This sac contains cerebrospinal fluid and nerve roots that would normally be contained within the spinal column. Depending on various factors, including the level of the myelomeningocele on the spine and the extent of nerve involvement, an affected infant might experience loss of lower extremity function and, perhaps, loss of bowel and bladder control. "Optimal treatment [of the myelomeningocele] consists of prompt surgical closure of the skin defect, preferably within 48 hours after birth, to prevent meningeal infection." Nelson, Behrman and Vaughan, *Textbook of Pediatrics* 1562 (12th ed. 1983). "It [myelomeningocele] is one of the most common developmental anomalies of the nervous system; the incidence ranges from 0.2-0.4/1000 births in different population groups.... Little is known about the etiology of myelomeningocele." *Id.* at 1561. If treated, almost all children with myelomeningocele will be ambulatory — they may walk with braces or crutches, or may use a wheelchair. Mental retardation is not directly associated with myelomeningocele if it is properly treated.

Hydrocephalus, a potentially serious anomoly often associated with myelomeningocele, occurs when too much cerebrospinal fluid accumulates within the cranium. If untreated, this condition causes the head to greatly enlarge and damages the developing brain. Treatment of hydrocephalus involves placement of a shunt that drains the excess fluid into another body cavity, most commonly the abdomen. *Id.* at 1568. Mental retardation sometimes occurs in infants with hydrocephalus; however, "[t]he mere presence of hydrocephalus does not necessarily imply a poor intellectual prognosis and does not preclude

independent existence." Mapstone, Rekate, Nulsen, Dixon, Glaser and Jaffe, *Relationship of CSF Shunting and IQ in Children with Myelomeningocele: A Retrospective Analysis*, 11 Child's Brain 112, 117 (1984). *See also* McLone, Czyzewski, Raimondi and Sommers, *Central Nervous System Infections as a Limiting Factor in the Intelligence of Children with Myelomeningocele*, 70 Pediatrics 338 (1982). If a child is treated with a shunt, then there is no necessary intellectual impairment.

It was the co-existence of hydrocephalus, the possibility of mental retardation, and the various other problems sometimes associated with myelomeningocele that led to the development of the discriminatory selection process at Oklahoma Children's Memorial Hospital that was used to determine which infants were to receive only the "supportive care," which involved denial of beneficial medical treatment leading predictably to death.

B. Social, Intellectual, and Other Nonmedical Criteria Were Considered in Determining Whether an Infant Should Be Denied Beneficial Medical Treatment.

When an infant with myelomeningocele presented at Oklahoma Children's Memorial Hospital, a "team" — consisting of a physician's assistant, a pediatrician, an orthopaedist, a neurosurgeon, an urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist — screened the child and the child's family; various diagnostic tests were performed. "If the child is found to have a lower lumbar or sacral lesion and no severe hydrocephalus or if there are no associated anomalies present, sac closure is recommended within a few days. If the lesion is at a high lumbar or thoracic level, severe hydrocephalus or other brain malformation is present, and/or other associated anomalies are noted, a

more formal meeting of the team is scheduled within 48 hours of admission." Gross at 452. Greater degrees of physical disability are associated with higher level lesions. The existence of a brain malformation indicates a greater possibility of mental retardation.

This formal "team meeting" to determine whether or not to provide an infant access to medical treatment occurred despite the fact, as the lead author of the report describing the selection process later conceded, that *"[b]abies considered to have a poor prognosis have a survival equal to that of babies with a good prognosis, if they receive early surgical treatment."* Gross, *Newborns with Myelodysplasia — The Rest of the Story*, 312 New Eng. J. Med. 1632, 1633 (1985) (emphasis added). Thus, the initial determination that some children ought to be considered for nontreatment bore no relation to whether or not treatment would enable the child to survive. It was based on the premise that some children *ought* not survive, even though they could if treated.

At the formal meeting "factors considered significant by Shurtleff et al (and to a lesser extent those considered significant by Lorber) were reviewed" by the team. Gross at 452.

Under Lorber's criteria, an infant would receive treatment unless he or she had a high level lesion, "gross enlargement of the head", *"severe paraplegia"*, or some other severe congenital defect. *Id.* at 450 (citing Lorber, *Early Results of Selection Treatment of Spina Bifida Cystica*, 4 Br. Med. J. 201 (1973) (emphasis added)). The presence of a high level lesion indicates a likelihood of a greater degree of physical disability; "gross enlargment of the head" might indicate a greater possibility of intellectual impairment. The use of "severe paraplegia" as a selection criterion certainly indicates that a prediction about the ability of a child to walk unaided would be a factor in deciding whether to provide the child with life-saving treatment.

Shurtleff's criteria differed from Lorber's "in that aggressive treatment was recommended for any infant, regardless of the level of the lesion, *if a good intellectual prognosis was noted.*" Gross at 451 (emphasis added). Shurtleff's criteria also included such factors as the existence of any major malformations that would preclude self-care as an adult, the economic and intellectual resources of the family, the distance the family lived from an appropriate facility, and commitments by social agencies to provide resources (such as a foster home or medical care costs) in determining whether or not a child would be treated. *Id.* (citing Shurtleff, Hayden and Lowser, *Myelodysplasia: Decision for Death or Disability*, 291 New Eng. J. of Med. 1005 (1974)).

In the selection process, the myelomeningocele team was also "influenced" by a pseudo-algebraic formula — QL = NE x (H + S) — published by Shaw in *Defining the Quality of Life*, 7 Hastings Center Rep. 11 (1977): "In the formula, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family and S is the contribution from society." Gross at 456. It was the myelomeningocele team's view "that external circumstances are crucially important in the outlook for the newborn with myelomeningocele. Thus, the treatment for babies with identical 'selection criteria' could be quite different, depending on the contribution from home and society." *Id.*

Following an evaluation of a child and the child's family under these intellectual, social, and economic criteria, the myelomeningocele team made a recommendation for either "vigorous treatment" or "supportive care." *Id.*

"Vigorous treatment" consisted of prompt sac closure (and thus prevention of infection), the insertion of a shunt if hydrocephalus were present, and all other indicated therapies.

"Supportive care" consisted of keeping the infant comfortable until death occurred. There was no surgery to close the opening in the infant's back. When hydrocephalus was present, the cerebrospinal fluid was allowed to accumulate causing gross enlargement of the infant's head and compression of the brain. "Antibiotics are not given for infection and sedation is not prescribed." *Id.* at 452. Thus, raging infections would spread throughout the central nervous system, gaining access through the opening in the spine, and would go untreated; a child would not be sedated for relief of pain. The predictable result was death, which occurred in every case in the reported program in which only "supportive care" was provided.

The authors of the article that described the program stated that the final decision between "vigorous treatment" or "supportive care" was left to the parents; and if the child is deemed unworthy of treatment, but the parents still want their child treated, then "their wishes are followed unless the operative risk is considered a direct threat to the baby's life." *Id.* There is no indication, however, that the parents were informed of the nonmedical, intellectual, social, and economic factors that entered into the recommendation. Moreover, it is "unrealistic for a physician to expect a father (mother is generally still hospitalized) to make such a difficult decision at a time of terrible emotional trauma. Invariably, in these circumstances, families make a decision based on information that is given to them by the pediatrician, pediatric neurologist or neurosurgeon. The great likelihood is that any one of these physicians will have his/her philosophy concerning what should be done and, therefore, whether intentional or unintentional, the information will be skewed. It is, therefore, the physician that is responsible for the immediate decision for or against treatment." Epstein, *Meningomyelocele: "Pitfalls" in Early and Late Management*, 30 Clinical Neurosurgery 366, 366-67 (1983). *See also* Homer, *Selective Treatment*, 87 Am. J. Nursing 309

(1984). Indeed, Dr. Gross, lead author of the report describing the selection process, admitted that "it takes a great deal of courage on the amount of parents to say, in the face of a recommendation from a physician, that they wish to go counter to that. They certainly do not have the background at the time the child is born to really know what is expected." Sherwood, *"Who Lives, Who Dies?" — Part II*, Cable News Network Documentary (February 22, 1984). *See generally* H. Turnbull & A. Turnbull, *Parents Speak Out: Then and Now* (1984).

Even though the authors asserted that the "final decision" was made by the parents, it is therefore unreasonable to presume that the parents could have made an intelligent and informed decision at the time of the child's birth. Parents would almost always rely on the expertise of the myelomeningocele team and follow their recommendation. And there is no evidence that the team informed the parents of the various nonmedical criteria — including criteria that related to the parents' social and economic status, geographical location, their presumed ability to cope with a disabled child, and the projected impact of the child on family life — that formed part of the basis for their recommendation. The members of the myelomeningocele team were the true decisionmakers at Oklahoma Children's Memorial Hospital, not the parents.

In sum, the selection process at Oklahoma Children's Memorial Hospital involved conjecture and the use of a number of nonmedical criteria — intellectual capacity, degree of paraplegia, family wealth and resources, geographical location — that had nothing to do with whether beneficial medical treatment was available to preserve the child's life or to correct an impairment. To the extent that such nonmedical criteria were employed, the participants played judge, jury, and seer for the children they evaluated, in effect recommending death for those they deemed unworthy of life.

C. Recommendations for Denial of Beneficial Medical Treatment Led to the Death of Twenty-four Infants.

Sixty-nine infants with myelomeningocele were seen at Oklahoma Children's Memorial Hospital during the five years that the reported study was in progress. Only thirty-six (52%) of these infants were recommended for "vigorous treatment." [1] The remaining thirty-three (48%) were recommended for "supportive care".[2]

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[1] When screening an infant and making a recommendation, the myelomeningocele team considered the criteria first published by Dr. Shurtleff as significant. Gross at 451. However, during the same period, 87% of the infants with myelomeningocele who presented to Dr. Shurtleff at Children's Orthopaedic Hospital and Medical Center in Seattle, Washington, received surgical (vigorous) treatment. Shurtleff, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 164, 164 (1984).

[2] The nature and results of this selection program were subsequently criticized in the medical literature. "[T]he Oklahoma team is not ambivalent about giving only supportive care to 48% of the children.... They were not even ambivalent about not treating five children with L-5 sacral lesions: children who will walk with minimal bracing." Freeman, *Early Management and Decision Making for the Treatment of Myelomeningocele: A Critique*, 73 Pediatrics 564, 565 (1984). "Do the authors seriously contend that the child with a high thoracolumbar lesion does not have the potential for human relationships? If so, I would suggest that they attend some of the youth programs at the national Spina Bifida Association of America meeting and educate themselves further in this regard." Venes, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 162, 162 (1984). .... "The reader unfamiliar with children who have myelomeningocele would believe, after reading this paper, that half of these children (48%) can be expected to have such a wretched existence that they should not be allowed to live.... In the past five years, we have treated all newborns who have myelomeningocele with full therapy.... None of our patients are in a vegetative state: all appear to enjoy life; and all interact well socially.... A review of the school performance of our older children reveals that 53% are at grade level or above, and 33% are at grade level but with special help." Liptak, Masiulis, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 165, 165 (1984).

(Footnote continued on following page)

Five of the infants recommended for nontreatment by the myelomeningocele team at Oklahoma Children's Memorial Hospital nevertheless eventually received vigorous medical attention[3]. Although two of these five children died at nine and seventy-two days of age respectively, the other three are alive and well. "One preschool aged boy with a thoracolumbar level lesion is able to stand and is considered to be doing well for his age. Another has microcephaly and is developmentally delayed, but is healthy. ... The third child has moved to another state, the child's name has been changed, and we have no current information." Gross, *In Reply*, 74 Pediatrics 166, 167 (1984). When treated, therefore, the children recommended for nontreatment were indeed capable of survival.

(Footnote continued from preceeding page)

"I read with disbelief the article by Gross et al. .... In our hands prompt treatment of unselected patients with myelomeningocele ensures that 85% survive, and of the surviving children, 73% have normal intelligence, 74.5% are community ambulators, and 85% are continent of urine on clean intermittent catherization.... The published opinion of the Spina Bifida Association of America, an organization composed principally of parents of children born with myelomeningocele, is dramatically opposed to the management put forth by Gross et al. The documented suffering appears to be of lessor [sic] concern to these families while education, access to transportation, and eventual employment are major concerns." McLone, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 162, 163 (1984). "The OCMH doctors quoted the writings of the Rev. Richard A. McCormick, Rose F. Kennedy professor of Christian ethics of Georgetown University, to support their selection method. But McCormick ... told *Newsday* that the OCMH rate of not operating on children with spina bifida is abusively high. They're abusing what I have said.'" Kerr, *Computing the Cost of Life*, Newsday, June 2, 1985 at 4, col. 1. "We would agrue that it is moral and ethically correct to treat all children born with a myelomeningocele and that no valid criteria exists for the selection of infants for nontreatment. McLone, *Results of Treatment of Children Born with a Myelomeningocele*, 30 Clinical Neurosurgery 407, 407 (1983).

[3] Of the remaining four infants recommended for "supportive care," three received delayed treatment and one moved to California at one month of age and was lost to follow-up. Gross at 453.

The twenty-four (35%) infants who were in fact denied medically indicated treatment during the five year period of the study all died within 189 days of birth. Gross at 453.

III. SECTION 504 WAS VIOLATED WHEN HANDICAPPED INFANTS WERE DENIED ACCESS TO MEDICAL CARE AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), provides in relevant part:

> No otherwise qualified handicapped individual in the United States, as defined in Section 706(7) of this title, shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

A "handicapped" individual is defined in 29 U.S.C. §706 (7)(B)(1982), as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such impairment." "An otherwise qualified handicapped person is one who is able to meet all of a program's requirements in spite of his handicap." *Southeastern Community College v. Davis*, 442 U.S. 397, 406 (1979).

Under the plain language of the Rehabilitation Act, therefore, the children subjected to the selection process were "handicapped individuals." *See United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 155 (2d Cir. 1984). They were "otherwise qualified handicapped individuals" because they were able to meet all the "requirements" of a medical program or activity — they could benefit from appropriate medical care, despite their handicaps. Moreoever, the selection process and treatment regimen that these

children were subjected to constituted discrimination in violation of the plain language of Section 504 of the Act.

A. Discrimination Between Infants with "Significant Handicaps" and Infants with "Minimal Handicaps" in the Initial Selection Process Violated the Plain Language of Section 504.

The first violation of Section 504 by Oklahoma Children's Memorial Hospital was the application of a selection process that permitted infants with a prognosis for a minimal handicap automatic access to medical treatment, while infants with a prognosis for a more significant handicap were placed in a formal selection process — despite the fact that "[b]abies considered to have a poor prognosis have a survival equal to that of babies with a good prognosis, *if they receive early surgical treatment.*" Gross, *Newborns with Myelodysplasia — The Rest of the Story*, 312 New Eng. J. of Med. 1632, 1633 (1985) (emphasis added).

This distinction drawn between an infant predicted to have a "significant handicap" and an infant predicted to have a "minimal handicap" — evidentially based on differing degrees of intellectual capacity and physical disability — clearly violated Section 504: It excluded an infant with a "significant handicap" from the participation in, and denied the infant the benefits of, the automatic medical treatment regimen accorded the infant with a "minimal handicap" for reasons based solely on the projected handicaps of the infant. *See generally* L. Kamin, *The Science and Politics of I.Q.* (1974).

B. Discrimination Among Infants with "Significant Handicaps" on the Basis of Inteilectual, Social, Economic, and Other Nonmedical Criteria Violated the Plain Language of Section 504.

Infants with a prognosis for survival with a significant handicap were compelled to meet other additional discriminatory criteria before they might be recommended

for access to medical treatment. These criteria included such factors as the predicted intelligence quotient (I.Q.) of the child, the degree of physical disability, the economic and intellectual resources of the child and family, the geographical proximity of the family to a medical facility, and the expected contributions to the child's care from home and society. Gross at 451, 456.

Using Lorber's criteria, the infant would receive only supportive care if "severe paraplegia" existed. Gross at 450; *see also* this brief at 9. This clearly discriminated solely on the basis of physical handicap, which is plainly contrary to the express purpose of Section 504.

Using Shurtleff's criteria, children with a good intellectual prognosis were recommended for vigorous treatment regardless of the level of the lesion. Shurtleff also considered the intellectual ability of the infant's parents in making a recommendation for or against treatment. Gross at 451; *see also* this brief at 10. The use of these factors clearly discriminated on the basis of mental handicap, contrary to Section 504.

Using Shaw's formula, the "natural endowment" of the infant is significant. Gross at 456; *see also* this brief at 10. "Natural endowment" would include both the projected intellectual capacity and the physical ability of the infant; both factors discriminated solely on the basis of handicap, in violation of Section 504.

The application of these criteria in the second phase of the selection process resulted in the discriminatory denial of treatment to infants based solely on the basis of their handicaps: The children who were recommended for and received only "supportive care" — food, water, and little more — were denied the benefits of, and participation in, the medical treatment regimen that was accorded those

children who were deemed worthy of care.[4] As a result, they died.

IV. CARLTON JOHNSON, AN INFANT WITH CONGENITAL DISABILITIES, WAS DENIED MEDICAL TREATMENT ON TWO SEPARATE AND DISTINCT OCCASIONS AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL IN VIOLATION OF SECTION 504.

Carlton Johnson, now almost 3 years of age, was born on September 12, 1982. Carlton, a black male infant, experienced respiratory distress at birth and was found to have myelomeningocele with hydrocephalus, microcephaly, and anemia.

Progress notes made by myelomeningocele team members in Carlton's medical record stated that he was

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[4] The Secretary of the U.S. Department of Health and Human Services interpreted Section 504 to prevent just this sort of discriminatory medical practice:

> In the case of an infant born with myelomeningocele, for example, the treatment which must be considered is surgery to close the protruding sac to prevent infection and other potentially fatal consequences. The "handicap" is the physical and/or mental impairment the infant is regarded as likely to have in future life. To the extent the myelomeningocele itself or other complications (such as respiratory problems, infection, anesthetic risk, or other factors) present, in the exercise of reasonable medical judgment, contraindications to the surgery, the infant is not able to benefit, in spite of his or her handicap, from the surgery. However, if the surgery would be medically beneficial, in that it would be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding infection or other fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is because of the handicap and in spite of the infant's being qualified to receive the surgery.

Dep't of Health and Human Services, Office of the Sec'y, *Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1621, 1637 (1984).

"not a good baby" and that "neurosurgery [was] not enthusiastic about shunting the child and closing the defect." The medical records state that information was given to his mother, Sharon Johnson, and that she would make the final decision. Mrs. Johnson, however, said that "the only thing they told me was about a shunt, and this, you know, after they told me about six months, that he would live six months without it, and then with it, a year, and I just figured, what's the sense in — he already suffers, so why should he suffer anymore?" Sherwood, *"Who Lives, Who Dies?" — Part 1*, Cable News Network Documentary (February 21, 1984). This statement indicated that Mrs. Johnson was not given adequate information to make a reasoned and informed decision.

Once it was determined that Carlton would be denied medical treatment, he was transferred to a nursing care facility for custodial care. His medical expenses at the hospital and the nursing home were paid by Medicaid.

Section 504 was violated when Carlton was denied access to beneficial medical treatment and was instead transferred to the nursing home. Carlton is a handicapped individual within the definition of 29 U.S.C. §706 (7)(B)(1982). He was "otherwise qualified" because he was capable of benefiting from medical treatment. Therefore, Carlton was discriminatorily denied medical treatment solely by reason of his handicap, in violation of the plain language of Section 504.

On October 17, 1982, Carlton returned to Oklahoma Children's Memorial Hospital with severe but treatable problems. His medical records show that Carlton was now experiencing severe respiratory distress and periods of apnea (cessation of breathing). On admission Carlton was cyanotic (bluish), and his condition was listed as guarded. Further clinical examination revealed bilateral otitis media (ear infection) and dehydration. Physician's orders stated that there were to be no laboratory tests to monitor

his condition; there were to be no intravenous fluids to correct the dehydration; there were to be no antibiotics for the ear infection. If Carlton were to suffer a cardiopulmonary arrest, he was not to be put on a respirator and no drugs were to be used. The only intervention that was to be allowed in this life-threatening situation was suctioning, giving of oxygen, and cardiac compressions.

Fortunately, Carlton did not experience a cardiopulmonary arrest. The only medical care that Carlton received during his hospitalization was oral-gastric tube feedings. He received no antibiotics for his ear infection. His dehydration was not treated with intravenous fluids and routine laboratory tests to monitor his condition were not performed. Despite this lack of ordinary medical treatment, Carlton's condition improved after he was rehydrated through the tube feedings. His ear infection cleared on its own.

This outrageous conduct clearly violated the plain language of Section 504. Carlton was denied beneficial treatment for his severe dehydration and ear infection — conditions totally unrelated to his handicap — solely because of his handicap. There is no question that a non-handicapped infant would have been aggressively treated in this life-threatening situation. This is an obvious and clear example of exactly the discriminatory conduct that Section 504 was enacted to prevent.

Carlton's medical records indicate that, with the exception of an emergency room visit at which time a hernia was diagnosed, he was not seen again at Oklahoma Children's Memorial Hospital until a year later in October, 1983. At that time it was becoming increasingly clear that he was not going to die. Both his head and the "sac" on his back had become grossly enlarged before Carlton was referred to neurosurgery for closure of the spine and placement of a shunt to treat his hydrocephalus.

It was not until January 30, 1984, however, that his spine was finally closed. A shunt was placed on February 7, 1984, and his hernias were repaired on February 17, 1984. As a result of delay, Carlton's head remains greatly enlarged. Further evaluation is needed to determine the loss of intellectual capacity and loss of ambulation — and the greater educational and rehabilitative services he will need — that occurred as a result of the delays in appropriate treatment.

V. THIS COURT SHOULD ACKNOWLEDGE THE AUTHORITY OF FEDERAL LAW TO PROTECT BOTH INFANTS WITH DISABILITIES AND THEIR PARENTS.

For children with disabilities and their parents to invoke the authority of Section 504 in the face of such discriminatory treatment, and in order that the federal government should have the power to investigate and protect both infants with disabilities and their parents from such discrimination, this Court must recognize that Section 504 applies to discriminatory medical practices.

A. The Injunction Currently in Force Has Prevented the Federal Government from Investigating the Selection Process at Oklahoma Children's Memorial Hospital.

On February 24, 1984, The Association for Retarded Citizens of the United States, The Association for Persons with Severe Handicaps, The Spina Bifida Association of America, The Down's Syndrome Congress, Nat Hentoff, and Martin Gerry[5] filed a formal complaint with the

[5] Mr. Nat Hentoff is a columnist for the *Village Voice* and a former member of the Executive Committee of the New York Civil Liberties Union; Mr. Martin Gerry is former Director of the Office for Civil Rights of the United States Department of Health, Education and Welfare (1975-1977), and is presently counsel to Wednesday Group of United States House of Representatives and to several national parents and disabilities rights organizations.

United States Department of Health and Human Services and the Department of Justice that alleged the selection process at Oklahoma Children's Memorial Hospital violated Section 504. The complaint requested that the program be investigated and enforcement action taken.

On June 29, 1984, however, the Director of the Office for Civil Rights of the Department of Health and Human Services notified the complainants that the Department of Health and Human Services was precluded from taking action under Section 504 due to the injunction issued by the district court in *American Hospital Association v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984). *See* Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment"*, 1 Issues in L. & Med. 15, 38-39 (1985). Consequently, no investigation of the selection process has been undertaken by the federal government.

Any similar decision by this Court holding that Section 504 does not apply to medical practices would permanently render the federal government powerless to investigate and to correct egregious forms of discriminatory conduct — even when performed by state actors in state institutions that receive federal funds, such as Oklahoma Children's Memorial Hospital.

There would be no question that the federal government could appropriately investigate and take measures to correct discriminatory medical decisionmaking based on the race of children in state-run, federally funded institutions. *See* Jones, *Bad Blood: The Tuskegee Syphilis Experiments* (1981). To hold that the federal government may not take similar steps for medical discrimination based on disability would be contrary to the intent of Congress and the plain language of Section 504.

B. Section 504 Must Apply to Discriminatory Medical Practices to Protect Parental Rights.

"This Court's decisions have by now made plain beyond the need for multiple citation that a parent's desire for and

right to 'the companionship, care, custody, and management of his or her children' is an important interest that 'undeniably warrants deference and, absent a powerful countervailing interest, protection.'" *Lassiter v. Department of Social Services*, 452 U.S. 18, 27 (1981) (citing Stanley v. Illinois, 405 U.S. 645, 651 (1972)).

At Oklahoma Children's Memorial Hospital, the myelomeningocele team purported to leave the final choice between supportive care or vigorous treatment to the parents: "If a pessimistic evaluation and prognosis has been offered the family but they still wish treatment, their wishes are followed unless the operative risk is considered a direct threat to the baby's life. (The reverse situation, refusal to consent to recommended surgery, did not occur.)" Gross at 452. But it is utterly unreasonable to expect the vast majority of parents to overrule the team's recommendation at a time soon after the traumatic birth of their disabled child. There is no indication that the parents were ever informed of the nonmedical intellectual, social, and economic criteria that formed the recommendation. *See* this brief at 12. The decision for treatment or "supportive care" was in fact made by the members of the myelomeningocele team in the form of a "recommendation" that almost all parents — in shock and without the emotional or informational resources to contest the "recommendation" — mechanically followed.

The recommendation of the team was based on criteria that violated the plain language of Section 504. When the infant was denied access to medical treatment in this manner, the parents' right to the care, custody, and management of their child was violated: The children who received only "supportive care" all died, completely severing the parent-child relationship. In this fashion, parental rights were denied on the basis of discrimination against their children with disabilities. Yet if Section 504 were held not to apply to such discriminatory medical

practices, then parents in such circumstances will be unable to claim the support of federal law to vindicate their rights and interests.

C. The Federal Government Must Have the Power to Investigate Allegations of Discriminatory Conduct in All Federally Funded Programs.

The Child Abuse Amendments of 1984, Pub. L. No. 98-457, tit. 1, §§121-28, 98 Stat. 1749, 1752-55 (codified as amended at 42 U.S.C. §§5101-5103 (Supp. 1985)), treat the withholding of medically indicated treatment from disabled infants with life threatening conditions as child abuse. As a condition of receiving state grants under the Child Abuse Prevention and Treatment Act, the State must have a procedure in its child protective service system to respond to reports of such abuse. If the state agency does not investigate incidents like the selection process at Oklahoma Children's Memorial Hospital, then it may be denied federal funds.[6]

The selection program at Oklahoma Children's Memorial Hospital, a state institution, was itself funded by federal funds insofar as the hospital and physicians were paid through Medicaid for services rendered to Carlton Johnson and other children subject to the selection process. Yet if Section 504 does not apply to discriminatory medical practices, then the federal government will not have the authority to stop the use of its funds to reimburse hospitals and physicians engaged in such discriminatory neglect. At the same time, it would be *required* to stop funding child

[6] It should be noted that there is no indication that the Oklahoma Children and Youth Services had even investigated the abusive practices at Oklahoma Children's Memorial Hospital, although they were a matter of public record. The Oklahoma Children and Youth Services and Oklahoma Children's Memorial Hospital are both under the authority of the Director and the Board of Commissioners of the Oklahoma Department of Human Services — the individuals ultimately accountable for the abusive practices at the hospital.

protection agencies that fail to pursue such instances of discriminatory child abuse. Such an absurd and inconsistent result can only be avoided by recognizing that Section 504 applies to discriminatory medical practices.

CONCLUSION

It is submitted that Section 504 of the Rehabilitation Act of 1973 should be held to apply to discriminatory medical practices and that the holding of the Court of Appeals for the Second Circuit to the contrary should be reversed.

Respectfully submitted,

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No. 84-1529

IN THE
SUPREME COURT OF THE UNITED STATES

October Term, 1985

MARGARET M. HECKLER, SECRETARY
OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

BRIEF AMICI CURIAE OF THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES; PEOPLE FIRST ORGANIZATIONS OF CALIFORNIA, IOWA, LOUISIANA, MICHIGAN, NEBRASKA, OREGON AND WASHINGTON; PEOPLE FIRST INTERNATIONAL; UNITED TOGETHER ORGANIZATIONS OF ARKANSAS, CALIFORNIA, FLORIDA, IDAHO, KANSAS, MASSACHUSETTS, MINNESOTA, AND MONTANA; SPEAKING FOR OURSELVES OF PENNSYLVANIA; CONSUMER ADVISORY BOARD OF MASSACHUSETTS; SELF-ADVOCATES OF CENTRAL NEW YORK; TEXAS ADVOCATES; WISCONSIN ADVOCATES; DISABLED IN ACTION OF PENNSYLVANIA; DISABLED IN ACTION OF NEW YORK; AND THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS

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No. 84-1529

IN THE

SUPREME COURT OF THE UNITED STATES

October Term, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICI CURIAE OF AMERICAN COALITION OF CITIZENS WITH DISABILITIES, *et al.*

INTERESTS OF AMICI CURIAE[1]

Amici are the largest national association and organizations from eighteen states founded by and comprised of persons with lifelong disabilities, in addition to the association of the protection and advocacy systems created by 42 U.S.C. §6012. All are keenly interested in effective civil rights deprivations such as denying handicapped persons medical services normally provided nonhandicapped persons. Many of amici's members lead active, fruitful, enjoyable lives today because as children they received lifesaving medical assistance, against the advice of physicians.

1. All parties have consented to the filing of this brief.

THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES, with eight million members, chiefly adults with longterm, severe handicaps, is the largest organization in the nation devoted to securing the civil rights of people with disabilities. Over 200 organizations in all of the fifty states are constituents of the Coalition, which has participated actively in the formulation of public policy respecting the rights of disabled citizens in the national congress, the executive, and the states, and has been recognized in every forum, as fairly and fully representative of disabled citizens. The formation on July 19, 1974 of the Coalition was evoked by the passage of Section 504. Its constituent organizations were major participants in the political and legislative processes resulting in Section 504 and in each of the enactments related to it. The Coalition was the major political actor in securing regulations to implement Section 504 and its 1974 amendments. The Coalition was one of the amici in *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984), whose majority opinion was viewed by the court below as dispositive of its judgment, but whose dissent by Circuit Judge Winter embraced the argument of several of the amici here.

PEOPLE FIRST ORGANIZATIONS OF CALIFORNIA, IOWA, LOUISIANA, MICHIGAN, NEBRASKA, OREGON and WASHINGTON; PEOPLE FIRST INTERNATIONAL; UNITED TOGETHER ORGANIZATIONS OF ARKANSAS, CALIFORNIA, FLORIDA, IDAHO, KANSAS, MASSACHUSETTS, MINNESOTA and MONTANA; SPEAKING FOR OURSELVES OF PENNSYLVANIA; TEXAS ADVOCATES; WISCONSIN ADVOCATES; and SELF-ADVOCATES OF CENTRAL NEW YORK are organizations established and led by retarded adults, most of whom are severely handicapped and many of whom are former or current residents of public institutions. Their common purpose: to speak for themselves rather than to let others speak for them and to know and exercise their rights as citizens, including the right to live in the community.

DISABLED IN ACTION OF METROPOLITAN NEW YORK and DISABLED IN ACTION OF PENNSYLVANIA were formed for the

purpose of securing full civil rights for all persons with disabilities in such areas as health care. They have been amici in several cases before this Court and DIA of New York was one of the amici in *University Hospital*.

THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS is comprised of the fifty independent State agencies designated by the Governors of the respective States and established pursuant to Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §6012, to protect and advocate disabled persons' rights. Section 504 has been the central, crucial instrument of these systems in their representation of handicapped children denied lifesaving medical assistance, and in attempting to secure the education of medical professionals to the real, and large, capabilities of severely disabled people.

SUMMARY OF ARGUMENT

1. The practice of denying lifesaving medical assistance to disabled children was an integral part of, and its continuing currency is firmly embedded in, the "history of unfair and often grotesque mistreatment" arising from the "prejudice and ignorance" acknowledged in *City of Cleburne, Texas v. Cleburne Living Center*, 105 S.Ct. 3249, 3262 (Stevens, *J.*, joined by Burger, *C.J.*, concurring), 3266 (Marshall, joined by Brennan & Blackmun, *JJ.*, concurring) (1985). The "regime" that permitted the destruction of handicapped people and their segregation from the rest of us for life continues to be expressed in withholding lifesaving medical assistance from children who have lifelong, severe disabilities. In 1915, a lifesaving operation was denied a disabled child because his "partial paralysis and the malformations were so great a bar to happiness or attainment, . . . there was no chance that life would bring this child anything better than an animal existence and imbecility. . . . I believe I have done the child, its parents . . . and the race a favor." Today the practice is justified in the same terms, *e.g.*, handicapped children have "no hope of achieving meaningful 'humanhood'."

2. Section 504 was the keystone of the "distinctive legislation response" invoked in *Cleburne*: a related series of statutes formulated and enacted by the national legislature during three Congresses, 1971-1975. Congress reversed the legacy of mistreatment and required admission of all disabled people — especially severely disabled people — to the benefits of our society. It was "a fairly won political victory." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting). Congress acted to end state-imposed segregation of severely disabled people, to end their isolation and to remove them from the status theretofore imposed upon them as "the expendables." Congress compiled a legislative record of unparalleled completeness on the modern understanding of the great capabilities of severely disabled people for learning, for productive work, for community participation, on modern techniques to support disabled people in the full realization of their capabilities, and on historical and continuing obstacles to achieving them.

The very matter at issue here — part of the "true story of exclusion and inadequate concern" chief sponsor Senator Humphrey said, 118 CONG. REC. 9495 (1972), was set out in the legislative history, *e.g.*: ". . . pediatricians . . . who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents; . . . doctors who urged [parents] to put [their child] in an institution and forget about him. There was so much willingness to eliminate the child, because they did not consider him a productive member of society." 118 CONG. REC. at 9500. The matter here is thus squarely encompassed by Section 504. Using all its powers, Congress in Section 504 opened equal citizenship fully to all severely disabled people. By its plain language and by Congress' richly articulate intention, Section 504 prohibits the denial of lifesaving medical assistance to severely disabled people.

3. Absent enforcement of Section 504, the legacy of "ignorance and prejudice," *Cleburne*, 105 S.Ct. at 3262, continues among medical professionals to work its destructive effect. Enforced, Section 504 calls an *informed* medical profession to itself, to an active respect for the lives of all people including, as the

Congress has directed, people who have lifelong, severe disabilities. "[A] decision not to correct a life-threatening digestive problem because an infant has Downs Syndrome is not a *bona fide* medical judgment." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting).

ARGUMENT

In *Meyer v. Nebraska*, 262 U.S. 390, 401-02 (1923), the Court stated that the historical practice of " 'putt[ting] away . . . the offspring of the inferior, or of the better when they chance to be deformed' " would "do . . . violence to both the letter and the spirit of the Constitution." Three years later counsel for Carrie Buck argued here that sterilization imposed by a State because of her "feeble-mindedness" was thus unconstitutional. The Court rejected that argument in *Buck v. Bell, Superintendant of the Virginia Colony for Epileptics and Feeble Minded*, 274 U.S. 200, 207 (1927), the apotheosis of this century's eugenic hysteria.[2]

Leaving handicapped children to die,[3] like compulsory ster-

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2. *Buck* expressed the era, ratified the view of the feebleminded as "a menace" by juxtaposing the country's "best citizens" (nonhandicapped persons) with those who "sap the strength of the state" (handicapped people), and, to avoid "being swamped with incompetence," held: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." 274 U.S. at 207.

The argument in *Buck* was not new. *See, e.g.*, Brief for the State of Kentucky, *Berea College v. Kentucky*, 211 U.S. 45 (1908) ("the progress, advancement, and civilization of the twentieth century . . . must be left not only to the unadulterated blood of the Anglo-Saxon-Caucasian race, but to the highest types and geniuses of that race. . . ."), *quoted in* R. KLUGER, SIMPLE JUSTICE 87 (1975).

3. This case concerns the denial of standard medical attention to redress an acute, lifethreatening medical condition for a child who also has, and will continue to have, a lifelong disability, *medical care which, if given, will allow the child to live*. This case raises *no* question concerning medical care that would only prolong dying. Characteristically, the matter here concerns retarded or physically handicapped children who require feasible, lifesaving surgery to correct a common, usually unrelated health problem (*e.g.*, an esophagus or stomach blockage, or a heart lesion, or an open spinal column)

ilization, exclusion from communities, and lifelong segregation of disabled people into destructive institutions[4] are part of the history of purposeful unequal treatment addressed by five Justices last Term in *Cleburne*, "the history," Justice Stevens with the Chief Justice wrote, "of unfair and often grotesque mistreatment" imposed "through prejudice and ignorance."[5] 105 S.Ct. at 3262. Describing the sources of the "regime of state-mandated segregation and degradation," Justice Marshall with Justices Brennan and Blackmun wrote:

> "Fueled by the rising tide of Social Darwinism, the 'science' of eugenics, and the extreme xenophobia of those years, *leading medical authorities* and others began to portray the 'feebleminded' as a menace to society and civilization . . . responsible in large degree for many if not all of our social problems." *Id.* at 3266 (emphasis added).[6]

An apparent majority of the *Cleburne* Court declined to address the historical legacy or to exact a heightened scrutiny of

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NOTES *(Continued)*

which will result in their death unless corrected.

The medical and bioethical literature draws a sharp distinction between postponing death, by maintaining the life of the body where the underlying, lifethreatening condition cannot be corrected, and lifesaving corrective surgery for a child who is and will be handicapped. *See, e.g.*, V. BARRY, MORAL ASPECTS OF HEALTH CARE 409 (1982); C. E. KOOP, THE RIGHT TO LIVE, THE RIGHT TO DIE 89-90 (1980); J. BEHNKE & S. BOK, THE DILEMMAS OF EUTHANASIA 103 (1975); *see also* Shaw, *et al.*, *Ethical Issues in Pediatric Surgery*, 60 PEDIATRICS 588, 590 (1977).

4. Contemporary institutional conditions have been found by the Court to be dangerous to those confined therein, *see Youngberg v. Romeo*, 457 U.S. 307, 315-16 (1982); *Pennhurst St. School & Hosp. v. Halderman*, 451 U.S. 1, 7 (1981), as they have been also in the cases of every public retardation institution to be scrutinized by a district court, *e.g.*, *Association for Retarded Citizens of N. Dak. v. Olson*, 561 F.Supp. 473, 484-88 (D.N.Dak.1982) (collecting some of the cases), *aff'd*, 713 F.2d 1391 (8th Cir. 1983).

5. The history of this era's state-approved denial of medical assistance to handicapped children who, with medical attention to correct an acute health condition, would not die is set forth *infra*, pp. 9-14.

6. The continuing prevalence and virulence of these views among medical professionals is set forth *infra*, pp. 15-18.

classifications disadvantageous to retarded people[7] on the ground that "the distinctive legislative response [of 1972-75] . . . belies a continuing antipathy or prejudice." *Id.* at 3256.[8]

This case concerns one of the related laws cited by the *Cleburne* majority as the "distinctive legislative response." Section 504 and each of the contemporaneously adopted statutes were enacted avowedly to reverse the history of prejudice, to admit disabled people fully to the benefits of equal citizenship. Amici submit, however, that the recent course of the Court's decisions on the very federal disability statutes invoked in *Cleburne* go a substantial distance toward nullifying the "legislative response."[9] This is the first case since *Cleburne* to deter-

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7. *But see* Justice Stevens' and the Chief Justice's distinct and apparently different views, 105 S.Ct. at 3261 & n.6. *And see* the views of Justices Marshall, Brennan and Blackmun, *id.* at 3265-68.

8. And belies, the Court majority wrote, "a corresponding need for more intrusive oversight by the judiciary." *Id.* Since *Cleburne* was a constitutional case the Court could not have meant to negate judicial oversight in the enforcement of a federal statute.

9. Section 504 — which, *Cleburne* says, "outlawed discrimination against the mentally retarded in federally funded programs," 102 S.Ct. at 3256 — was held three days earlier not to be privately enforcible by a federal court against a state agency, *Atascadero St. Hosp. v. Scanlon*, 105 S.Ct. 3142 (1985), and in *Southeastern Community Coll. v. Davis*, 442 U.S. 397, 405 (1979), was construed not to require "substantial modifications in [State] programs to allow disabled persons to participate."

The Developmentally Disabled Assistance and Bill of Rights Act of 1975, Section 111, 42 U.S.C. §6010 — in which, *Cleburne* says, "the federal government . . . has also provided the retarded with the right to receive appropriate treatment, services and habitation in a setting that is least restrictive of [their] personal liberty," 102 S.Ct. at 3256 — was held in *Pennhurst I*, 451 U.S. 1, 16 n.12 (1981), to create "no rights whatsoever."

The Education of the Handicapped Act, 42 U.S.C. §§1400-15 — which, *Cleburne* says, requires an " 'appropriate' education" for all handicapped children, 105 S.Ct. at 3257 — was held in *Board of Education v. Rowley*, 458 U.S. 176, 200 (1982), to require merely an education 'sufficient' to confer *some* educational benefit upon the handicapped child" (emphasis added), despite Congress' requirement that education authorities systematically use demonstratedly effective educational programs, 20 U.S.C. §§1400(b)(7), 1413(a)(3).

mine whether one of these statutes shall be given its plain meaning, whether the undertaking of the other two Branches to reverse the regime and admit severely disabled persons to the benefits of our society shall be given judicial respect.

Here the issue is whether Section 504, a plenary civil rights statute[10] which facially and categorically prohibits any "exclu[sion]" of handicapped persons by reason of a handicap "from the participation in any program or activity receiving federal financial assistance" as well as "deni[al] of the benefits of . . ." any assisted program or activity, and any "discrimination" in such programs, does so.[11]

NOTES *(Continued)*

Section 503 of the Rehabilitation Act of 1973, 29 U.S.C. §793, nearly uniquely among statutes explicitly requires "affirmative action to employ and advance in employment qualified handicapped individuals" by "part[ies] contracting with the United States" — thus by its terms conferring duties upon employers, and opportunities for productive work on severely disabled people, which significantly exceed the employment rights established by the Civil Service Regulation recited in *Cleburne*, 105 S.Ct. at 3256 — has been held by nine Courts of Appeal *not* to be enforceable in a private right of action with *certiorari* six times denied here, *e.g.*, *Hodges v. Atchinson Rwy. Co.*, 728 F.2d 414 (10th Cir.), *cert. denied*, 105 S.Ct. 97 (1984); *but see Drennon v. Phila. Gen. Hosp.*, 428 F.Supp. 809 (E.D. Pa. 1977) (Higginbotham, *J.*); *Rogers v. Frito Lay, Inc.*, 611 F.2d 1074, 1085 (5th Cir.) (Goldberg, *J.*, dissenting), *cert. denied*, 449 U.S. 889 (1980); *Davis v. United Airlines, Inc.*, 662 F.2d 120, 127 (2d Cir. 1981) (Kaufman, *C.J.*, dissenting), *cert. denied*, 456 U.S. 965 (1982).

10. *New York St. Ass'n for Retarded Children v. Carey*, 612 F.2d 644, 649 (2d Cir. 1979). *See also NAACP v. Wilmington Med. Ctr.*, 599 F.2d 1247, 1258 & n.47 (3d Cir. 1979); *Lloyd v. Regional Transp. Auth.*, 548 F.2d. 1277, 1280-84 (7th Cir. 1977).

11. The practice in issue here violates each clause of Section 504, but, amici submit, is most directly addressed as "an exclusion from" and "a denial of the benefits of" assisted programs and activities. The "program or activity" here is the federally funded hospital. To the extent any programs so assisted (and the vast majority are) may exclude or deny its benefits to handicapped children, *Grove City Coll. v. Bell*, 104 S.Ct. 1211, 1220 (1984), presents no concern.

I. HISTORICALLY AND NOW, ACTING FROM IGNORANCE AND PREJUDICE ESTABLISHED IN AN EARLIER ERA, PROVIDERS OF HEALTH SERVICES HAVE DENIED PERSONS WITH LIFELONG DISABILITIES THE BENEFITS OF THEIR SERVICES AND HAVE, WITH SINGULARITY ON THE BASIS OF A HANDICAP, WITHHELD LIFESAVING MEDICAL SERVICES.

Section 504 and the contemporaneous statutes of which it is the keystone represent a conscious decision by Congress to reverse "the regime of segregation and degradation" imposed on disabled people in the early decades of the century, to eliminate the legacy of "ignorance and prejudice" acknowledged in *Cleburne*. The practice at issue here is of the regime and continues for reasons of ignorance and prejudice rooted in the regime.

The *New York Times*, November 18, 1915, in a Page One report, "Defective Babe Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Country's Good," gives an historical example of the awful practice:

> "John Bollinger, the boy baby condemned as a hopeless defective and therefore not operated on, died early this evening in the German-American Hospital. The child was five days old. . . .
>
> "Its life, Dr. H. J. Haiselden, the attending physician, said, might have been saved by an operation, but this he did not feel justified in performing. The partial paralysis and the malformations, he said, were so great a bar to happiness or attainment that he did not feel justified in saving the baby from the death which nature ordained. . . .
>
> "Coroner Hoffman said tonight: 'I do not believe there will be an inquest. The case is not different from many others. . . .'

"State's Attorney Hayes said privately that he approved the physician's refusal to act in the case. Officially, since there appeared a basis for legal action, he would express no opinion. . . .

"Dr. Haiselden in discussing his action said tonight: 'I rest with my conscience. There was no chance that life would bring this child anything better than an animal existence and imbecility. . . . I believe I have done the child, its parents, who agree with me, and the race a favor in taking the course I did. . . .'

"Many persons had asked permission to take the baby to their homes and have it cared for by other surgeons. Women pleaded, and at least one vented her wrath in epithets of the bitterest nature."[12]

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12. The baby died of an imperforate anus that could have been treated with simple surgery. Dr. Haiselden, the hospital's Chief of Staff and a staunch eugenicist who in his practice sterilized "defective" children, announced to the press that he would allow the child, who otherwise would be a "burden to society," to die of autointoxication. S. L. Kuepper, Euthanasia in America, 1890-1960, at 70 (Rutgers Univ. diss. 1981), *citing* Columbus (Ohio) Evening Dispatch, Nov. 17, 1915, at 2; Chicago Daily News, Nov. 19, 1915, at 3; Chicago Tribune, Nov. 17, 1915 at 1. Dr. Haiselden suggested that the child, like other "defectives," would be prone to criminality, and called on other physicians to follow his example, to tend only the fit, "so that by the weeding out of our undesirables we decrease their burden and ours and lay the foundation for a normal human race." Philadelphia Inquirer, Nov. 19, 1915, at 7. Even when ordered by the Health Commissioner to operate, Dr. Haiselden steadfastly refused, stating that he did "not believe it would do justice to the human race." Kuepper, *supra* at 71. Most physicians who spoke out on the issue agreed with Dr. Haiselden, and The Medico-Legal Society adopted a resolution supporting him. *Id*. at 73. Dr. W. C. Woodward, the District Health Officer, observed that the very existence of the controversy showed that "the public conscience with respect to such cases is changing. . . . A few years ago, the condemnation of mother and physician would have been universal." *Id*., *citing* Chicago Tribune, Nov. 18, 1915, at 2 . The *Medical Standard*, a physicians' journal, sponsored a roundtable at which seven of ten participants agreed that death was an acceptable alternative for severely handicapped babies. *The Defective Child*, 89 MEDICAL STANDARD 35-42 (1916). The mother of another "Haiselden baby," a child with microcephaly, later deeply regretted that her child had been allowed to die and urged parents of handicapped infants in need of lifesaving

This report is not an isolated example but is part of the "regime." "By the latter part of the century and during the first decades of the new one," Justice Marshall noted in *Cleburne*, beliefs concerning handicapped people "underwent a radical transformation," 105 S.Ct. at 3266, and social preoccupation with eugenics "reintroduced an attitude favoring the killing of defective children."[13] Some physicians, in fact, advocated that the unfit be actively eliminated. In 1906, a distinguished Chicago physician endorsed the "destruction" of handicapped persons on eugenic grounds: "In strict justice to society . . . and in many cases in all kindness to the defective himself, every degenerate who is useless to himself, a menace to the health of society, and is shown to be incurable should be effectively eliminated by destruction."[14] A respected New York physician, W. Duncan McKim, advocated the elimination of all severely handicapped children, including "idiots," most "imbeciles," and the greater number of epileptics, for society's protection, via a "gentle, painless death" by the inhalation of carbonic gas.[15]

Although the eugenic hysteria of the era abated, physicians continued to support the view that the "defective" and the "feeble-minded" should die. In the wake of a physician's admission that he had put to death a child "clearly doomed to imbecility," the *Journal of the American Medical Association* observed that doctors frequently face this situation and generally decide it their way without interference. A Nobel Prize winner at the Rockefeller Institute similarly urged that "sentimental prejudice . . . not obstruct the quiet and painless disposition of incurables, criminals, and hopeless lunatics."[16]

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medical treatment to save their lives. Chicago Tribune, May 8, 1938, §1, at 2.

13. D. B. Shurtleff, *Myelodysplasia: Management and Treatment*, 10 CURR. PROBS. IN PEDIATRICS 1, 8 (1980).

14. G. FRANK LYDSTON, M.D., DISEASES OF SOCIETY 568 (1906).

15. D. MCKIM, HEREDITY AND HUMAN PROGRESS 189, 193 (1900).

16. *The Right to Kill*, TIME, Nov. 18, 1935, at 53-54. *See also* Kennedy, *The Problem of Social Control of the Congenital Defective*, 99 AM. J. PSYCH. 13-16 (1942) (advocating involuntary euthanasia of 60,000 retarded persons in institutions and five times as many outside, since in these "hopeless" cases "we have no fear of error").

This stark history is of course of the regime of segregation and degradation[17] which by force of state statute deemed retarded people to be "unfit for citizenship."[18] In every state in inexorable fashion handicapped persons were legislatively declared a "menace to the happiness . . . of the community,"[19] "unfitted for companionship with other children,"[20] a "blight on mankind"[21] whose very "presence"[22] in the community was "detrimental to normal" people.[23]

Official policy was to "purge society"[24] of these "anti-social beings,"[25] to "segregate [them] from the world,"[26] so that they "not . . . be returned to society"[27] since a "defect . . . wounds our citizenry a thousand times more than any plague."[28] Disabled persons simply did not have the "rights and liberties of normal people."[29] The District of Columbia Board of Charity

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17. The general history of the regime was detailed in APPENDIX A, COMPENDIUM OF PURPOSEFUL STATE ACTION FOR THE SEGREGATION AND EXCLUSION OF RETARDED PERSONS IN THE FIFTY STATES AND THE DISTRICT OF COLUMBIA, BRIEF AMICI CURIAE OF ARC/US, *et al.*, *City of Cleburne, Tex. v. Cleburne Living Ctr.*, 105 S.Ct. 3249 (1985).

Appendix A to this Brief is a COMPENDIUM OF THE MEDICAL LITERATURE OF THE ERA, DESCRIBING PHYSICIANS' PARTICIPATION IN THE GENERAL REGIME AND THEIR RATIONALE FOR ELIMINATING HANDICAPPED CHILDREN.

18. 1920 Miss. Laws 294, ch. 210, §17 *quoted in Cleburne*, 105 S.Ct. at 3267 (Marshall, *J.*, concurring).

19. 1919 Ala. Acts 739, No. 568, §7.

20. 1909 Wash. Laws 260, tit. I., subch. 6, §2.

21. REPORT OF THE VT. SCHOOL FOR THE FEEBLE-MINDED 17-18 (1916).

22. REPORT OF THE R.I. SCHOOL FOR THE FEEBLE-MINDED 21 (1910).

23. CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, FIRST BIENNIAL REPORT 41 (1905).

24. WISCONSIN BOARD OF CONTROL, BIENNIAL REPORT 321 (1898).

25. REPORT OF THE COMMISSION ON SEGREGATION, CARE AND TREATMENT OF FEEBLE-MINDED AND EPILEPTIC PERSONS IN PENNA. 43 (1913).

26. THIRTY-SIXTH ANNUAL REPORT OF THE INDIANA SCHOOL FOR FEEBLE-MINDED YOUTH 14 (1914).

27. FIRST BIENNIAL REPORT OF THE BOARD OF COMMISSIONERS OF NEBRASKA INSTITUTIONS 10 (1915).

28. FOURTH BIENNIAL REPORT OF THE BOARD OF TRUSTEES OF THE UTAH STATE TRAINING SCHOOL 3 (1938).

29. FOURTH BIENNIAL REPORT OF THE SOUTH DAKOTA COMMISSION FOR SEGREGATION AND CONTROL OF THE FEEBLE-MINDED 3 (1932).

urged Congress, and it agreed, to authorize putting handicapped people away since they were "not much above the animal."[30] Handicapped people were "not far removed from the brute,"[31] not quite persons, but "by-products of unfinished humanity"[32] who were to be segregated for the benefit "of society,"[33] "to relieve society of 'the heavy economic and moral losses arising from the existence at large of these unfortunate persons.' "[34] It was important to find a "way of getting rid of these kinds of cases."[35] Government reports labeled handicapped people "a parasitic, predatory class,"[36] a "danger to the race,"[37] "a blight and a misfortune both to themselves and to the public"[38] whose role "in discounting social progress is by far the most potent influence for evil under which society is struggling today."[39]

State officials actively inculcated fear of handicapped persons, especially retarded persons, directed their identification and removal from the community, and coerced the assistance of physicians, health workers, and a variety of others to do so, *even* against parental instincts to harbor them.[40] State statutes di-

30. *District of Columbia Appropriations Bills, Hearings Before the Comm. on Appropriations*, 67th Cong., 2d Sess. 96 (Jan. 13, 15, 1923).

31. MENTAL DEFECTIVES IN VIRGINIA: SPECIAL REPORT OF THE BOARD OF CHARITIES AND CORRECTIONS TO THE GENERAL ASSEMBLY OF 1916, at 20.

32. Baldwin, *The Causes, Prevention and Care of Feeble-Minded Children*, in PROCEEDINGS OF THE TEXAS CONFERENCE OF CHARITIES AND CORRECTIONS AT ITS SECOND ANNUAL MEETING 87 (1912).

33. *E.g.*, 1919 Ga. Laws 379, No. 373, §3.

34. *Cleburne*, 105 S.Ct. at 3267 n.9 (Marshall, *J.*, concurring), *quoting* 1915 Tex. Gen. Laws 143, ch. 90, §§1, 2.

35. *Connecticut School for Imbeciles: Hearings on H. B. No. 644 Before the Joint Standing Committee on Humane Institutions* 20 (typed transcript, Feb. 25, 1915) (statement of Mr. Kerner of Waterbury).

36. REPORT OF THE VERMONT SCHOOL FOR FEEBLE-MINDED CHILDREN 17-18 (1916).

37. *Report of the Legislative Visiting Committee*, WISC. SEN. J. 263 (48th Leg. Sess.).

38. THIRTEENTH BIENNIAL REPORT OF THE KANSAS SCHOOL FOR FEEBLE-MINDED YOUTH 12 (1906).

39. MENTAL DEFECTIVES IN INDIANA: THIRD REPORT OF THE COMMITTEE ON MENTAL DEFECTIVES 6 (1922).

40. *E.g.*, 1915 N.C. Sess. Laws 337-38, ch. 266, §3; 1931 S.D. Sess. Laws 200, ch. 153, §§3(b), (c); 1918 Ky. Acts 171, ch. 54, §30; 1917 Or. Laws 739,

rected others to put away the child if the parent or relative "should neglect or refuse" to do so.[41] One statute made it a criminal offense punished by a $200 fine for a *parent* to refuse.[42] Statutes required parents to "waive all right to remove such inmate thereafter either permanently or for a limited time,"[43] to keep from society disabled children "whose parents or guardians are averse to such actions."[44] States officially made the judgment that "the presence of the unfortunate child in the home"[45] was "more tragic than any known disease,"[46] and a "menace to . . . the family."[47]

The views and practices of physicians in issue here and the vulnerability of new parents of handicapped children[48] are the

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NOTES *(Continued)*

740, ch. 354, §§5; CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, EIGHTH BIENNIAL REPORT 51 (1918); 21ST BIENNIAL REPORT OF THE KANSAS TRAINING SCHOOL 3 (1922).

41. 1920 Miss. Laws 294, ch. 210, §17; 1921 W. Va. Acts 480, ch. 131, §4(a); *see* 1919 Ala. Acts 740, No. 568, §9 ("notwithstanding the family or relatives may object thereto"); 1909 Okla. Sess. Laws 538, ch. 34, art. 2, §8.

42. 1905 Wash. Laws 135, ch. 70, §9.

43. 1905 Mich. Pub. Acts 169-70, No. 121; 1919 N.J. Laws 508, ch. 217, §3; *accord*, 1919 Mont. Laws 198, ch. 102, §9; 1909 N.D. Sess. Laws 317-18, ch. 213, §1.

44. CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, BIENNIAL REPORT 30 (1916); *accord*, FIRST BIENNIAL REPORT OF THE BOARD OF COMMISSIONERS OF NEBRASKA INSTITUTIONS 11 (1915) (need for disabled children to be "detained in the institution against the desire of the parent").

45. REPORT OF THE R.I. SCHOOL FOR THE FEEBLE-MINDED 21 (1910).

46. FOURTH BIENNIAL REPORT OF THE UTAH TRAINING SCHOOL 3 (1938).

47. 1885 Cal. Stats. 198, ch. 156, §8; 1906 Md. Laws 653, ch. 362. These authoritative state instructions were the counterpoint to President Kennedy's Special Message, February 5, 1963, requesting Congress "to reinforce the will and capacity of our communities to meet these problems in order that the communities, in turn, can reinforce the will and capacity of individuals and individual families." 109 Cong. Rec. 1842. The disability rights laws of 1972-1975 were a response to this call and were enacted to reverse the instructions of the earlier era. *See* Argument II *infra*, pp. 19-28.

48. Who after all, before they in one swift moment have become parents of children with a lifelong handicap, are just people schooled in the ordinary ignorance and prejudice an entire era was dedicated to establishing.

fruits of this period. The singular exception for persons with lifelong disabilities in the otherwise constant and professionally fundamental commitment of medical professionals to sustain life[49] is expressed still in precisely the terms popularized and established in that "most xenophobic era," *Cleburne*, 105 S.Ct. at 3266.

During the current decade there has been an explosion of articles in medical journals reporting in detail the practice of withholding lifesaving medical assistance from children who have lifelong handicaps, and setting forth justifications for doing so.[50] The studies reveal that many physicians, a majority in some specializations, oppose lifesaving surgery for babies with lifelong disabilities.[51] These publications, in language and substance exactly akin to the "science" of the earlier era, *Cleburne*, 105 S.Ct. at 3266, assert three rationales: (1) on a cost-benefit basis, society

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49. For the historical commitment of the medical profession to life and the singularity of this exception, *see* O. Temkin, *et al.*, RESPECT FOR LIFE IN MEDICINE, PHILOSOPHY AND THE LAW (1977); D. CRANE, THE SANCTITY OF SOCIAL LIFE (1975); J. DUFFY, THE HEALERS (1976); E. FREIDSON, PROFESSION OF MEDICINE (1975); I. ABT & F. GARRISON, HISTORY OF PEDIATRICS (1965).

50. Gross, *et al.*, *Early Management and Decision-Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983); Affleck, *Physicians' Attitudes Toward Discretionary Treatment of Down's Syndrome Infants*, 18 MENTAL RETARDATION 79 (1980); Todres, *et al.*, *Pediatrician's Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977); Shaw, *et al.*, *supra* note 3; Darling, *Parents, Physicians and Spina Bifida*, 7 HASTINGS CTR. REP. 10 (1977); Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 N.ENG.J. MED. 890 (1973). *And see* D. CRANE, *supra* note 49; *cf.* J. Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BRIT. MED. J. 201 (1973).

51. In a survey of members of the Surgical Section of the American Academy of Pediatrics, for example, 76.8% of pediatric surgeons and 49.5% of pediatricians reported they would not insist upon surgery in a newborn with intestinal atresia if the infant also had Down Syndrome, while only 7.9% and 2.6% respectively would not if the child was nonhandicapped. The physicians surveyed ranked the infant's "potential quality of life," probable IQ, and adverse effects on the family high among criteria for deciding whether to withhold surgery. Shaw, *et al.*, *supra* note 3, at 590. Massachusetts pediatricians confessed similar beliefs for a baby with Down Syndrome and an even more striking preference for nontreatment of a baby wtih severe spina bifida (67% said they would recommend to the parents that surgery not be performed). Todres, *et al.*, *supra* note 50, at 197-99.

would be better off without the child;[52] (2) the burdens the child would impose on the family are greater than any benefits to be derived;[53] (3) the intrinsic value of the child's life is very little.[54] Each asserted rationale is counterfactual, is based on ignorance and prejudice, and is contrary to congressional findings.[55] Physicians' categorical assumption that severely handicapped children are a familial or societal burden are, in amici's considerable experience, plainly wrong.[56] Competitive employment and supported work programs have demonstrated without doubt the capacity of severely handicapped adults for productive employment.[57] Just as others, severely disabled persons experience

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52. *E.g.*, "no child with Down's Syndrome ever grew up to be self-sustaining," Crile, *The Right to Life*, Medical Tribune, December 19, 1984; severely handicapped persons have "no prospect . . . of employment," Lorber, *supra* note 50, at 202; Down Syndrome persons are not "capable of being useful," Shaw, *et al.*, *supra* note 3, at 595; their "potential usefulness" is nil, D. CRANE, *supra*, note 49, at 55.

53. *E.g.*, "As far as having a mongoloid child, I can't come up with anything satisfying about it, I can't think of anything good it does." Darling, *supra*, note 50, at 11. Down syndrome children bring "frustration and sadness," "rarely" love and happiness into the home. Shaw, *et al.*, *supra* note 3, at 595.

54. Severely handicapped persons have "little or no hope of achieving meaningful 'humanhood' " and "little or no capacity to love or be loved," Duff & Campbell, *supra* note 50, at 892; and a poor "quality of life," Gross, *et al.*, *supra* note 50, at 450, 456; physicians define severely handicapped persons' lives as "intolerable." Darling, *supra*, note 50, at 13.

55. Argument II, *infra*, sets forth the congressional findings.

56. Darling, *supra* note 50, at 11 (survey reports parents love their disabled children and view their own parenting situation positively); Burt, *Constitutional Law and the Teaching of the Parables*, 93 YALE L. J. 455, 495 (parents of handicapped persons hope for their children's full inclusion in the community); *See Wyatt v. Aderholt*, 503 F.2d 1305, 1312 & n.8 (5th Cir. 1974) (segregation of handicapped persons for their families' convenience morally and constitutionally impermissible); Wald, *State Intervention on Behalf of 'Neglected' Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975) (parents' failure to provide lifesaving medical treatment constitutes abuse at common law); Joint Commission on Juvenile Justice Standards, Standards Relating to Abuse and Neglect Recommended by the IJA/ABA (1981) (failure to provide lifesaving medical treatment constitutes abuse and neglect).

57. WEHMAN, COMPETITIVE EMPLOYMENT: NEW HORIZONS FOR THE SEVERELY DISABLED (1981); G. T. BELLAMY, VOCATIONAL HABILITATION OF SEVERELY RETARDED ADULTS: A DIRECT SERVICE TECHNOLOGY (1979).

joy and contribute to society.[58]

The familiar rationale for eliminating children with severe handicaps arises still from the familiar ignorance. In 1962, the President's Panel on Mental Retardation found unacceptably high the frequency of "decisions [by medical professionals] based on erroneous expectations as to the child's capacity" and concluded "physicians need special orientation to the nature and implications of physical and intellectual disabilities."[59]

The American Academy of Pediatrics reports[60] that 50.5% of pediatricians identify as "insufficient" their learning about ". . . handicapped children" and The Academy itself identified "handicapping and chronic conditions" foremost among "subjects in which education content is inadequate" and among "the underemphasized areas in pediatric residencies."[61]

In Nebraska, for example, where a system of community services for retarded people had long since been well established, most pediatricians (81%) and general practitioners (79%) still regularly recommended institutionalization even for

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58. J. P. EDWARDS, WE ARE PEOPLE FIRST: OUR HANDICAPS ARE SECONDARY (1982); P. WILLIAMS & B. SHOULTZ, WE CAN SPEAK FOR OURSELVES (1982).

59. PRESIDENT'S PANEL ON MENTAL RETARDATION, REPORT TO THE PRESIDENT: A PROPOSED PROGRAM FOR NATIONAL ACTION (1962). Two decades later, still, a survey comparison of pediatricians with nonmedical professionals found:

> "[P]ediatric practitioners respond less optimistically than educators or psychologists toward the mentally retarded child. Often they may begin their examination with an already established poor prognosis of the child's future functioning, resulting in serious implications for the type of placement options presented to the family home, institution, special school." Wolraich & Siperstein, *Assessing Professionals' Prognostic Impression of Mental Retardation*, 21 MENTAL RETARDATION 8, 10 (1983). "Pediatric training," the authors observe "typically involves minimal exposure to mental retardation." *Id.* at 10.

60. THE FUTURE OF PEDIATRIC EDUCATION: A REPORT BY THE TASK FORCE ON PEDIATRIC EDUCATION (1977).

61. Significantly, modern services to severely disabled people depend upon educators, occupational and physical therapists, vocational specialists and psychologists, not physicians. *See* Amici Brief of AAMD, TASH *et al.*

"moderately" retarded children.[62] Given the deficits of knowledge among physicians it is not surprising they should be supplied instead by familiar historically sponsored and established prejudice and stereotypes.

The President of the American Academy of Pediatrics has suggested that too much has been made of surveys, that pediatricians are better informed about handicaps than they were even in the 1970s;[63] however, there is ample evidence that the practice of refusing life-saving medical treatment may be even more common than survey studies would predict.[64]

In any event, Congress has flatly rejected the practice by its enactment of Section 504 and the other disability laws of the early 1970s. It is to those laws, the Congressional findings upon which they are based, and the Congress' purposes in enacting them, that amici now turn.

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62. Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Retarded*, 13 MENTAL RETARDATION, Dec., 1975, at 10 (1975) (40% of parents advised to institutionalize their child (86% within a year of diagnosis), but "not one of these children is presently residing in an institution").

63. Strain, *The Decision to Forego Life Sustaining Treatment for Seriously Ill Newborns*, 72 PEDIATRICS 572 (1983).

64. A report on the results of selection of handicapped newborns for treatment between 1977 and 1982 at Oklahoma University Health Sciences Center showed that babies were provided — or denied — treatment based on such factors as their estimated intelligence and ambulatory potential, according to a "formula" that also factored in the "contribution anticipated from his home and family and society." Gross, *et al.*, *supra* note 50, at 456. A study has documented that surgeons at a teaching hospital were actually *less* likely to perform surgery on Down syndrome children with heart defects than survey studies would predict. D. CRANE, *supra* note 49, at 96-98.

II. BY ITS PLAIN MEANING, ITS STRUCTURE, AND THE EXPRESS INTENTION OF THE CONGRESS SECTION 504 WAS ENACTED TO REVERSE THE REGIME OF SEGREGATION AND DEGRADATION EARLIER IMPOSED UPON HANDICAPPED PERSONS AND TO BAR THE WITHHOLDING OF LIFE-SAVING MEDICAL ASSISTANCE.

The plain language of Section 504 prohibiting any "exclus[ion] from" or "denial of the benefits of any federally assisted program or activity" on the ground of handicap, and its "legislative heritage" as a civil rights statute in which the other two Branches conclusively adopted the analogy of handicap to race[65] are sufficient to command a reversal here. Amici do not rehearse that argument, as it is set forth compellingly in Judge Winter's dissenting opinion in *University Hospital*, 729 F.2d at 161-62, and addressed in the briefs of others here. Rather, amici direct the Court's attention to the legislative history of Section 504 and the several related, contemporaneous enactments, for there is nothing in this case that Congress did not comprehend in the course of formulating those statutes.

The significance — historic and legal — of Congress' decision to establish handicap as a basis for civil rights protection cannot be overstated. The legislative history of Section 504 and each of the directive statutes enacted during four legislative years, 1972-1975,[66] show that Congress understood the history of

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65. Section 504 was patterned after Title VI and Title IX and was originally introduced as an amendment to Title VI. When that amendment was inserted into vocational-rehabilitation legislation then pending, its language, principle and intent was carried forward into §504, as the Court recognized unanimously in *Alexander v. Choate*, 105 S.Ct. 712, 718 & n.13 (1985).

66. The Court has frequently directed that legislative history of related enactments be read to inform each of them. *E.g.*, *Albemarle Paper Co. v. Moody*, 422 U.S. 405, 416 (1975). Section 504 was proposed, considered and enacted contemporaneously with the Education of the Handicapped Acts ("EHA") of 1974 and 1975, 20 U.S.C. §§1400-1415; the Developmentally Disabled Assistance and Bill of Rights Act of 1975, 42 U.S.C. §§6000, *et seq.*; the Rehabilitation Act of 1973 proper and the succeeding Rehabilitation Amendments of 1974, 29 U.S.C. §§701, *et seq.*; and the remaining provisions of Title V, the civil rights title, of the Rehabilitation Act, 29 U.S.C §§791-795. The

disability discrimination, was moved by the continuing destructive effect of the regime of state-mandated segregation and degradation, including its perpetuation in the matter here, and acted to reverse that regime, root and branch, and to eliminate its legacy. In short, Congress said, of course a severe, lifelong disability is handicapping, but more handicapping have been the "extreme xenophobic," "grotesque" reactions of society to persons with disabilities. This congressional history is the primary guide to construing Section 504.

On the basis of the extensive and pointed legislative record the decision below should be reversed and Section 504 and its related enactments given their intended meaning and effect.[67] Otherwise "handicapped persons will be deprived of a fairly won political victory and exposed to the possibility of future decisions excluding other services from Section 504 . . ." *University Hospital*, 729 F.2d at 162-63 (Winter, *J*., dissenting).[68] "It is not enough to say to the Congress, we see what you are driving at . . . but we shall go on as before." *Johnson v. United States*, 163 F. 30,32 (lst Cir. 1908) (Holmes, *J*., on circuit).

NOTES *(Continued)*

EHA and the Bill of Rights Act were initially proposed in 1972 and the subjects of hearings, reports and floor action in 1973, 1974 and 1975. The Rehabilitation Act proper was initially proposed in 1972 and was the subject of hearings, reports and floor consideration in 1972, 1973 and 1974. The hearings and reports from this extensive legislative record are compiled in Appendix B.

67. It would, for example, benefit handicapped persons insufficiently and betray the congressional undertaking were it to be held that Acts of Congress require lifesaving medical assistance after birth but do not prohibit institutional segregation. As Joseph Goldstein has written:

> As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than either assume full responsibility for the treatment, care, and nurture of such children or honor the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life. *Medical Care for the Child at Risk* in W. GAYLIN & R. MACKLIN, WHO SPEAKS FOR THE CHILD 153 (1982).

68. *See also Cleburne*, 105 S.Ct. at 3257.

In Section 504, and the related enactments, Congress had in mind not only the mildly or moderately disabled, the cosmetically handicapped, those who found it relatively easy to "make it"; rather Congress acted knowingly and expressly especially on behalf of those with *severe*, usually *lifelong disabilities* (and acted to supply the conditions under which they can make it). Congressman Vanik, Senator Humphrey, and Senator Percy, introducing what became Section 504, each focused upon "the most severely handicapped." 117 CONG. REC. 45974 (1971); 118 CONG. REC. 526 (1972).[69] Handicapped persons who had been "shunted aside, hidden, ignored," "behind closed doors,"[70] 117 CONG. REC. at 45974, "the 'expendables'," as Senator Humphrey described them, 118 CONG. REC. at 9495, were the primary intended beneficiaries of Section 504.[71]

The central purpose of Section 504, as numerous statements made in the course of its formulation show, was to disestablish the regime of "segregation and degradation." As Senator Humphrey squarely put it: "The fundamental fact one confronts

69. A unanimous Court in *Alexander*, 105 S.Ct. at 718 nn.13 & 15, said the views of Congressman Vanik and Senators Humphrey and Percy are to be given particular weight in interpreting the legislative history of Section 504. Ultimately, Section 504 was cosponsored by 60 House members and 20 Senators. 118 Cong. Rec. 9495 (1972), and the Rehabilitation Act of 1973 including Section 504 was passed unanimously. 1973 CONG. Q. ALM. 557, *et seq*.

70. Resolving that the Congress would "no longer tolerate the invisibility of the handicapped in America," 117 Cong. Rec. at 45974 (statement of Rep. Vanik), the progenitors of Section 504 understood the sustaining mechanism of ignorance and prejudice, as Justice Marshall wrote in *Cleburne*, the "lengthy and continuing isolation of the retarded has perpetuated the ignorance, irrational fears and stereotyping that have long plagued them," 105 S.Ct. at 3267.

71. In the Rehabilitation Act — "the major vocational-rehabilitation bill then pending" — into which Congress inserted 504 and other civil rights provisions, *Alexander*, 105 S.Ct. at 718 n.13, Congress required that vocational-rehabilitation "serve *first* those with *the most severe* handicaps." 29 U.S.C. §§701(1), 721(a)(5); *see also id*. §§741(a), 750(a), 762, 772(b), 774(b). The EHA was enacted in 1974-75 by Congresses similarly cognizant that the greatest number of handicapped children theretofor excluded from school altogether had severe disabilities, and required that State and local education authorities "establis[h] priorities for providing a free public education to all handicapped children . . . with respect to handicapped children, within each disability, with the *most severe handicaps*." 20 U.S.C. §§1412(3), 1414(a)(6).

is . . . the segregation of [these] Americans from society. . . . This bill [addresses] handicapped children, youth and adults who suffer the profound indignity and despair of isolation, discrimination and maltreatment." Congress understood the historical origins of current conditions in "the deliberate segregation of the handicapped" and in their "resulting invisibility," 118 CONG. REC. at 9497-98 (Sen. Humphrey), in the historical but continuing view that "handicapped children were a physical threat[,] uneducable, . . .[and], nauseating," 117 CONG. REC. at 45974 (Rep. Vanik), in the regime established on the basis of the "danger" and "hopeless incapability" of disabled people, 118 CONG. REC. at 526 (Sen. Percy).

Section 504 was enacted as a sharp break with that history, to repudiate it, to reverse its legacy. "In essence, our amendment will give the handicapped their rightful place in society." 118 CONG. REC. at 526 (Sen. Percy). [Section 504] carries through the intent of the original bills . . . to end the virtual isolation of children and adults from society." *Id.* at 32310 (Sen. Humphrey).[72] To do so, Congress understood, required reor-

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72. Ending the distinctive institution of segregation itself, the keystone creation of the historical regime, was a central purpose and intended effect of Section 504:

> "In this country we still have the snake-pit mental institutions — institutions for confinement not treatment, where brutality and unexplained deaths are common. . . ." 117 CONG. REC. at 45974 (Rep. Vanik).
>
> "I am calling for public attention to three-fourths of the nation's institutionalized retarded people who live in public and private residential facilities which are more than 50 years old, functionally inadequate, and designed simply to isolate those persons from society." 118 CONG. REC. at 525 (Sen. Humphrey).
>
> ". . . retarded and other handicapped people must become as much as possible a part of society, living and working in the community. . . . The vehicle for integrating the retarded into the community is the group home where retarded children — or adolescents or younger or older adults — can live beyond the wards of institutions with the assistance of non-retarded house-parents." *Id.* at 9500-01; *accord, id.* at 526; 117 CONG. REC. at 42293-94 (Sen. Percy).

In the Senate Report accompanying the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §6010, whose plain terms were in

dering the basic relationship between handicapped people and the so-called "normal" society.[73]

In the course of resolving to eliminate the historical regime, root and branch, Congress came to a knowledge of the capabilities and prospects of severely disabled people entirely different from that which underlay the regime and that continues today still to be boldly offered in justification of withholding lifesaving medical assistance. Congress' systematic finding plainly underlying Section 504 and every one of the related enactments, is that *severely* disabled people, as a matter of fact, can *live* and *learn* and *work productively* in — and as integral members of — the community and that it is impermissible even to suggest that people with severe disabilities are "expendable" or that "their lives are not worth living." For example, as to the facts, Congressman Vanik recognized that "handicapped children, even the most severely handicapped, do learn when given the chance to participate in educational programs tailored to meet their special needs." 118 CONG. REC. at 526. Contemplated throughout the legislative history of Section 504 was the "opportunity for education, job training, productive work," *id.* (Sen. Percy), "a productive and [even] financially independent life" for handicapped persons "no matter how severe his or her degree of disability,"[74]

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harmony with the Court's opinion in *Cleburne (but see Pennhurst I*, 451 U.S. 1 (1982)) — the same Senate Committee that incorporated Section 504 wrote: "It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. [T]he fact [is] that most of these institutions are anachronisms, and that rapid steps should be taken to phase them out." S. Rep. No. 160, 94th Cong., 1st Sess. 32-33 (1975).

73. Congress acted, in short, to codify the right of disabled people to "equal citizenship" and "insist[ed] that the organized society treat each individual as a person, one who is worthy of respect, one who 'belongs . . .' presumptively forbid[ding] the organized society to treat an individual either as a member of an inferior or dependent caste or as a non-participant." Karst, *Supreme Court, 1976 Term — Forward: Equal Citizenship Under the Fourteenth Amendment*, 91 HARV. L. REV. 1, 6 (1977); *see also* Baker, *Outcome Equality or Equality of Respect*, 131 U. PA. L. REV. 933 (1983).

74. *See* note 71 *supra*.

117 CONG. REC. at 42294; 118 CONG. REC. at 526.[75]

While formulating "the distinctive legislative response" of Section 504, its 1974 affirmation, and its related enactments, Congress — in three years of hearings on the EHA, three years on the Rehabilitation Act, and three years on the Developmentally Disabled Assistance and Bill of Rights Act — compiled an unprecedented legislative record on the modern understanding of the capabilities of severely disabled people, on modern techniques of assisting disabled people to realize them and historical and contemporary obstacles to achieving them.[76] Based on these findings and in a full exercise of its powers, including particularly its powers to enforce the Fourteenth Amendment, the Congress enacted Section 504 and each of the related enactments. Neither this nor any judicial forum is the place to quarrel with the findings of Congress, with its purposes or with the plain meaning of its enactments, nor is a hospital neonatal ward the place for any such contest. Lifesaving health services are among the federally assisted services Congress sought to reach by Section 504, legislating to open these and all other federally funded benefits fully to severely handicapped persons.[77]

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75. "Where," Senator Humphrey asked, "is the cost-effectiveness in . . . consigning them to 'terminal' care is an institution?"

76. Upon that record the Congress found, in enacting the EHA: "[D]evelopments in the training of teachers and in diagnostic and instructional procedures and methods have advanced to the point that . . . state and local educational agencies can . . . provide effective special education and related services to meet the needs of handicapped children." 20 U.S.C. §1413.

77. Respondent AHA complains that any such application of Section 504 would constitute impermissible "affirmative action" under *Southeastern Community College v. Davis*, 442 U.S. 397, 411-12 (1979). Opp. Cert. Brief of Respondent AHA, at 26. This argument ignores the important gloss placed on that "severely criticized" *Southeastern* passage by *Alexander v. Choate*, 105 S.Ct. at 721 n. 20. The regulation at issue here requires no "fundamental alteration in the nature of a program," *id. quoting Davis*, 442 U.S. at 410, but merely, as Section 504 specifies, that the benefits of that program be provided handicapped persons in a "meaningful" fashion, *Alexander*, 105 S.Ct. at 721. Indeed, the official analysis of the HHS regulation for Section 504 specifies that the agency intended from the beginning "to give particular attention in its enforcement of Section 504 to eliminating discrimination against persons with the severe handicaps that were the focus of concern in the Rehabilitation Act

Rising on the floor of the House on December 9, 1971 to introduce Section 504, Congressman Vanik stated: "Mr. Speaker, the treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights" and immediately singled out the "100,000 *babies* [who] are born *with defects*" annually among the "masses of the handicapped [who] live and struggle among us, often *shunted aside*, hidden and *ignored*. How have we as a nation treated these fellow citizens?" 117 CONG. REC. at 45974 (emphasis added). Mr. Vanik described in no uncertain terms the "confinement without treatment," the "brutality," and the "unexplained deaths." *Id.* "But," he concluded, enactment of Section 504 would mean that Congress would "no longer tolerate the invisibility of the handicapped in America." *Id.*

Rising one month later on the floor of the United States Senate, Senator Humphrey stated:

> "Mr. President, I introduce . . . a bill to amend the Civil Rights Act of 1964 to insure equal opportunities for the handicapped by prohibiting needless discrimination in programs receiving Federal financial assistance. No longer dare we live with the hypocrisy that the promise of America should have one major exception: Millions of children, youth, and adults with mental or physical handicaps."

118 CONG. REC. at 525. "These people have *the right to live*," Senator Humphrey said, and "to know the dignity to which every human being is entitled." *Id.* (emphasis added). And Section 504 was designed to insure, among other equality guarantees, the "right to health," which, he said, was "fundamental." *Id.*

Leaving no room for dispute, Senator Percy followed Mr. Humphrey with a statement of cosponsorship, referenced a Concurrent Resolution he sponsored, and stated that Section 504 would "ensure that the handicapped will receive the basic rights to which every human being is entitled," rights that were "well

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of 1973." 45 C.F.R. Part 84, App. A, ¶3, 42 Fed. Reg. 22686 (1977). In *Consolidated Rail Corp. v. Darrone*, 104 S.Ct. 1248 (1984), the Court held that the 1978 amendment to Section 504 codified the HHS regulation. *See Alexander*, 105 S.Ct. at 722 n.24, 721 n.21, 724 n.27.

documented in the *Record* when the Concurrent Resolution was introduced." 118 CONG. REC. at 526. Senator Percy emphasized that Section 504 was to be the "legislative solution" to the problems outlined in the Concurrent Resolution. "These rights were clearly and forcefully spelled out in Senate Concurrent Resolution 52, . . . which I was privileged to co-sponsor. They are rights that must now be given the force of law. . . ." *Id.* at 11790. That Concurrent Resolution flatly stated:

> "*A mentally or physically handicapped person has the right to proper medical care and physical restoration* and to such education, training, rehabilitation, and guidance as will enable that person to develop his ability and potential to the fullest possible extent, *no matter how severe his or her degree of disability*."

S. Conc. Res. No. 52, 92d Cong., 1st Sess., 117 CONG. REC. 42294 (1971) (emphasis added).

Congress was well-aware that physicians and other professionals were often responsible for denigrating the abilities of severely handicapped people. Senator Humphrey stated that his bill was for "millions of handicapped children, youth, and adults who suffer the profound indignity and despair of *isolation, discrimination, and maltreatment*. It is essential that the right of these forgotten Americans to equal protection under the laws be effectively enforced through prohibiting their exclusion from services receiving Federal assistance." 118 CONG. REC. at 9495 (emphasis added). Describing the "categories of people who would be directly affected — children who are mentally retarded, physically handicapped" and condemning "the segregation of millions of Americans from society — suggesting a disturbing viewpoint that these people are not only forgotten but perhaps expendable," *id.*, Senator Humphrey requested and received unanimous consent to reprint in the *Record* a news series titled "The Expendables" which, the Senator stated, "la[id] before the public the true story of exclusion and inadequate concern experienced by hundreds of handicapped children." *Id.* The reports were laced with stinging criticisms of physicians, psychologists and other professionals who seriously devalued the

developmental potential and, indeed, the very lives of handicapped children. One example concerned a retarded child:

> "When Reuben first began working with an 11½-year-old-child we will call Jimmy, *doctors said the child had virtually no measurable intelligence and had a physical condition making it impossible for him to grasp and hold objects in his hands* . . . . Gradually, the attendant over a few days moved her hand away from the child's hand to his wrist. Already *the medical prediction was refuted* . . . It took another week to get Jimmy to feed himself independently without even the slightest pressure of the attendant's hand at his elbow."

118 CONG. REC. at 9499 (emphasis added). The report also documented the experience of parents who were told by pediatricians and others that their children's lives would be worthless:

> "They also spoke angrily about *pediatricians and purported experts in the field of retardation — the professionals who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents*. . . .
>
> "Mrs. Hosey remembers *a pediatrician* who called her child 'a moron,' and *a neurologist* who said, 'If you had eight hours a day and 20 years, maybe you could teach Stevie to feed himself.'
>
> "She also remembers with a touch of bitterness *other doctors who urged her and her husband to put Stevie in an institution and forget about him*. 'There was so much *willingness to eliminate the child*, because they did not consider him a productive member of society,' she said, 'but we only thought of him as our child and we did not feel guilty about him.' . . . [She felt] a deep anger at the system: A system which regularly has written off certain categories of handicapped children, their children, as hopeless."

118 CONG. REC. at 9500 (emphasis added). The "direct solution" to these "denial[s] of civil rights of millions of Americans," Senator Humphrey insisted (118 CONG. REC. at 9495), and Congress agreed, was the enactment of Section 504.

Section 504 was adopted to counter the view that they cannot learn or function. Senator Percy's statement on the Concurrent Resolution, like Representative Vanik's and Senator Humphrey's on the bill, emphasized that "it is intolerable to hide the handicapped" out of a belief that they are "hopelessly incapable" when Congress recognized and established with the enactment of Section 504 that "even the most severely handicapped" can learn and thrive. 118 CONG. REC. at 526.

III. SECTION 504 CALLS PHYSICIANS TO THEIR PROFESSIONAL SELVES.

Section 504 does not interfere with medical judgment. To the contrary, Section 504, if enforced, would call the medical profession to itself. By Section 504, Congress has prohibited disability-based exceptions to physicians' constant, fundamental commitment to sustain life. "[A] decision not to correct a life-threatening digestive problem because an infant has Downs Syndrome is not a bona fide medical judgment." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting).

Allowing a handicapped baby to die violates Section 504 if it involves withholding not "extraordinary" measures but ordinary treatment that routinely would be performed if the child were not handicapped.[78] Refusal to perform lifesaving medical treatment because the child is handicapped is not a medical decision, but a decision based upon factors irrelevant to the child's medical needs.[79]

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78. "Extraordinary" treatment is defined by the American Medical Association as "the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent." Statement of the House of Delegates, December 4, 1973, *reported in* 227 J.A.M.A. 728 (1974). For the difference between extraordinary treatment and the treatment at issue here, see *supra* note 3.

79. Rachels, *Active and Passive Euthanasia*, 292 N. ENG. J. MED. 78, 80 (1975).

Physicians improperly present as "medical"" recommendations to parents of handicapped children nontreatment recommendations that in fact are based on the judgment that the child is better off dead than alive and handicapped.[80] Doctors know of parents' trust in their expertise[81] and of their vulnerability in the turmoil of the newborn period.[82] Physicians resort to medical nomenclature to disguise the nonmedical grounds of the recommendation: by labeling as "extraordinary" lifesaving treatment that is, in fact, quite ordinary[83] or by applying "selective criteria" for treatment that purport to be medical but in fact are based on other, nonmedical, values.[84]

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80. *See* the recommendation offered to parents by Dr. Judson Randolph, Surgeon-in-Chief at Children's Hospital of the National Medical Center in Washington, D.C.:

> "Your baby has two problems: one is correctible, the other, brain damage, is not correctible. Since I can only correct one of them and am unable to correct or alter in any way the other, I would prefer that you let me care for your baby, but without operating on him." *Surgical Decision — Is There a Choice?* in ROSS CONFERENCE ON PEDIATRIC RESEARCH, ETHICAL DILEMMAS IN CURRENT OBSTETRIC AND NEWBORN CARE 58 (1973). *See also* Randolph, *Consultant's Note*, 10 HOSP. ROUNDS, Sept., 1974, at 23.

81. *"At the end it is usually the doctor who has to decide the issue*. It is not only cruel to ask the parents whether they want their child to live or die, it is dishonest, because in the vast majority of cases, the parents are consciously or unconsciously influenced by the doctor's opinion." Shaw, *Dilemmas of Informed Consent in Children*, 289 N. ENG. J. MED. 885, 886 (1973) (emphasis added). *And see* Ingelfinger, *Bedside Ethics for the Hopeless Case*, 289 N. ENG. J. MED. 914 (1973) ("the onus of decision-making ultimately falls on the doctor in whose care the child has been put.")

82. Fost, *Counseling Families Who Have a Child With a Severe Congenital Anomaly*, 67 PEDIATRICS 321, 322-23 (1981).

83. *See, e.g.*, Shaw, *et al.*, *supra* note 3, at 594.

84. Dr. John Lorber, who pioneered the active treatment of spina bifida in the 1960s, found one problem with his results: "Improved techniques did not lead to fewer, but to more, handicapped children, because with the increased survival rate many more severely affected infants survive" causing "grave family, social, educational, financial and community problems." Lorber, *Spina Bifida Cystica: Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future*, 47 ARCH. OF DISEASE IN CHILDHOOD 854 (1972). For "selective criteria" used by physicians, *see* Stein, *et al.*, *Selection for Early Treatment in Myelomeningocele: A Retrospective Analysis of Various Selection*

Section 504, which secures to handicapped persons the "rights and liberties of normal people,"[85] requires precisely that physicians base their decisions *on* medical judgment, and that physicians extend the same respect to disabled people as customarily the profession does, and must, to all life.

CONCLUSION

The decision of the Court of Appeals should be reversed.

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NOTES *(Continued)*

Procedures, 54 PEDIATRICS 553 (1974) and Shurtleff, *et al.*, *Myelodysplasia: Decision for Death or Disability*, 291 N. ENG. J. MED. 1005 (1974), both stating that retardation is an appropriate reason for withholding surgery.

85. Compare the 1932 South Dakota government report, *supra* note 29.

APPENDIX A

COMPENDIUM OF THE MEDICAL LITERATURE OF THE ERA (1896-1920) DESCRIBING PHYSICIANS' PARTICIPATION IN THE GENERAL REGIME AND THEIR RATIONALE FOR ELIMINATING HANDICAPPED CHILDREN

Amici submit this brief historical note to describe the historical context in which the twentieth-century practice of allowing handicapped infants to perish at birth emerged in its present form and was pursued for the same reasons it is today.

The twentieth-century practice differs radically from other manifestations of infanticide in Western history. Before the twentieth century, victims of infanticide were not exclusively handicapped children; most commonly, they were nonhandicapped children who were unwanted for economic or social reasons.[1] Nor, before the twentieth century, did physicians sanction the practice in the guise of "medical judgment." Infanticide was practiced on a large scale in eighteenth and nineteenth century Europe because of extreme poverty, economic scarcity, and social forces that fostered illegitimacy but severely punished the unwed mother.[2] The 1890 edition of the *Encyclopedia Britannica* described the situation in late-nineteenth century England:

> "The modern crime of infanticide . . . is closely connected with illegitimacy in the class of farm and domestic servants. The crime is generally committed by the mother for the purpose of completing the concealment of her shame and, in other cases . . . to escape the burden of her child's support."[3]

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1. Radbill, *A History of Child Abuse and Infanticide*, in R.E. HELFER & C.H. KEMPE, eds., THE BATTERED CHILD 3 (1968).

2. M. PIERS, INFANTICIDE: PAST AND PRESIDENT 65 (1978); Williamson, *Infanticide: An Anthropological Analysis*, in M. KOHL, ed., INFANTICIDE AND THE VALUE OF LIFE 61, 69 (1978).

3. 13 ENCYCLOPEDIA BRITANNICA 3 (9th ed. 1890), *quoted in* D. BAKAN, SLAUGHTER OF THE INNOCENTS (1971).

By the end of the nineteenth century, a strong reaction against infanticide and other forms of child abuse had developed. In the United States, the child protection movement gained momentum from the formation of voluntary societies for the prevention of cruelty to children during the nineteenth century and culminated in the formation in 1912 of the Children's Bureau, which the federal government established to investigate and to report "upon all matters pertaining to the welfare of children and child life among all classes of our people."[4]

The movement to prevent child abuse at first did not distinguish between handicapped and nonhandicapped children. But in the first two decades of the twentieth century, the extreme devaluation and dehumanization of disabled persons that arose during that xenophobic and eugenist Era selectively affected the way handicapped infants were treated at birth. Until the late nineteenth century, physicians had neither opportunity nor inclination to engage in selective nontreatment of handicapped infants. Most infants were born at home; and before the development of asepsis, internal surgery was extraordinary.[5] Nor was the handicapped infant seen as a threat to the family or to society. Nineteenth century physicians' view of the infant's endowment at birth differed radically from that adopted by their twentieth-century counterpart under the influence of the determinist, hereditarian views widely held in that Era. Nineteenth century physicians thought that the infant remained malleable after birth and that its development could best be understood as a dynamic response to its environment. They made no absolute distinction between the innate and the acquired, but saw the relation of innate infirmity and achievement as "a protean affair of tendency and predisposition, not of discrete and unitary qualities."[6]

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4. Radbill, *supra* note 1; BAKAN, *supra* note 3, at 48-49.

5. M. VOGEL, THE INVENTION OF THE MODERN HOSPITAL 13, 60-61 (1980); G. ROSEN, THE STRUCTURE OF AMERICAN MEDICAL PRACTICE 1875-1914, at 44 (1983).

6. C.E. ROSENBERG, NO OTHER GODS: ON SCIENCE AND AMERICAN SOCIAL THOUGHT 27, 47 (1976). To the physician and others in the nineteenth

During the early twentieth century, many physicians adopted the determinist hereditarian and eugenicist attitudes of the Era and attempted to incorporate those attitudes into their practice of medicine. This adoption was not universal, however, for many physicians of the Era correctly perceived the fatal contradiction between their duty to heal and an ideology that preached that only the "fit" are worthy to be healed and that the physician's duty is to the race rather than to the patient.[7] Physicians and others of the Era understood that in practicing eugenics, the physician served *social* rather than therapeutic ends.[8]

During the first two decades of the twentieth century, eugenic ideas were widely discussed among physicians in medical journals, in scholarly papers, and at meetings of medical societies. Improvement of the race through regulation of marriage, sterilization of the unfit, and above all, the segregation of the feeble-minded were topics on which there was wide agreement that eugenic solutions were needed and that physicians had an important role to play in implementing them. Physicians who embraced eugenicism perhaps did so in their own self-interest[9] and emphasized the importance of their role in improving the race. "[I]f it is possible to perfect mankind," a surgeon of the U.S. Public Health Service wrote in 1915, "the means of doing

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century, deformity evoked a sense of man's fallen nature, a sense of the sin and inability borne by all men, "immanent yet not *quite* inevitable," susceptible to amelioration by habit, training, and moral activism. *Id.* at 38.

7. *See, e.g.*, Mason, *Some Thoughts on the Eugenic Movement*, 20 MED. REV. OF REVIEWS 146 (1914).

8. *Symposium on Euthanasia*, 19 MED. REV. OF REVIEWS 143, 152 (views of Professor R. Burton Opitz); Block, *The Social Aspects of the Bollinger Case*, 22 MED. REV. OF REVIEWS 122 (1916); *Euthanasia Again*, 88 MED. RECORD 925 (1915).

9. Hereditarian doctrines enabled physicians to reassure, to "find and intone an explanation" for what they could not cure, and thereby convert what could not be cured into a less threatening and more manageable reality. Such ideas were useful, therefore, in helping justify the social position of practicing physicians. C. E. ROSENBERG, *supra* note 6, at 50-51.

it will be in the medical profession."[10]

Editorials in medical journals urged that uniform laws on marriage be enacted to prevent the unfit from reproducing, and that the public be made aware of "the importance of fit and unfit matings";[11] doctors advocated that marriage be reformed and its traditions replaced by "laws based upon the broader needs of the race."[12] They admonished women to develop "a racial consciousness" and approach the choice of a husband as "a fundamental eugenic problem,"[13] for "the science of eugenics sets a new valuation upon the reproductive function."[14] Lest exhortation be insufficient, Chicago physicians participated in another incentive to "stimulate the physical improvement of the race": a baby show based on strict eugenic principles. The judges evaluated the young contestants for defects of the skin, bones, muscles and teeth, and even attempted to estimate the babies' I.Q.; the avowed purpose of the exhibition was "the stimulation of an ambition to beget and rear physically sound and normal offspring."[15]

Physicians seized upon the studies of the Jukes, the Kallikaks and other "defective strains" to prove that unfit marriages were "a crime against society, when as a result of them the unfit are born into the world."[16] If articles in leading medical journals

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10. Friedman, *Physical Basis for Moral and Mental Deficiencies*, 87 MED. RECORD 637 (1915).

11. *Some Problems in Genetics* (editorial), 20 MED. REV. OF REVIEWS 518 (1914); *Practical Eugenics*, 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 338 (1913).

12. Young, *Some of the Possibilities of Constructive Eugenics*, 20 MED. REV. OF REVIEWS 256 (1914).

13. *Women and Eugenics* (editorial), 21 MED. REV. OF REVIEWS 259 (1915).

14. *Eugenics and Religion*, 21 MED. REV. OF REVIEWS 200 (1915).

15. *Baby Shows and Eugenics*, 39 MED. STANDARD 227 (1916).

16. Satterthwaite, *Some Problems in Genetics*, 86 MED. RECORD 141 (1914); R. DUGDALE, THE JUKES: A STUDY IN CRIME, PAUPERISM, DISEASE AND HEREDITY (G.P. Putnam, 1877) (reprinted by Arno Press, 1970); H. GODDARD, THE KALLIKAK FAMILY: A STUDY IN THE HEREDITY OF FEEBLE-MINDEDNESS (Macmillan, 1912). *See* the favorable review of The Kallikak Family in the *Journal of the American Medical Association: A Natural*

are representative, physicians were heavily in favor of legislation mandating compulsory sterilization of retarded persons, despite their doubts about its constitutionality.[17] At a 1914 symposium on sterilization of the unfit, four out of five physicians who participated agreed that "defectives" should be sterilized.[18]

Support for the regime of state-imposed segregation of retarded persons that was established during the Era was, to judge from published comment, virtually unanimous. Writing in the leading medical journals of the day, physicians claimed that retarded persons were the "greatest social menace of the age,"[19] a "contamination that is polluting the stream of our social life,"[20] a "source of danger to the community."[21] "The moron is ubiquitous, and has been so, but his ability to harm has only recently been emphasized."[22] The editor of the *Journal of the American Medical Association* lamented that the "man in the street" did not yet realize the economic and social problems connected with the feeble-minded and that "this class is increasing enormously in all civilized countries."[23]

Typical of medical opinion of the day are the views of a physician in Kansas City, who, claiming that "segregation of the feeble-minded is advocated by medical authority the world over," argued that the feeble-minded must not be allowed to

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Object-Lesson in Heredity, 59 J.A.M.A. 1545 (1912). The intentionally distorted methodologies and survey results of Dr. Goddard and others are taken apart painstakingly and devastatingly in J.D. SMITH, MINDS MADE FEEBLE: THE MYTH AND LEGACY OF THE KALLIKAKS (1985).

17. *See, e.g., Eugenics and the Limitation of Offspring*, 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 266 (1913); Orton, *The Procreative Regulation of Defectives and Delinquents*, 58 J.A.M.A. 2021 (1912).

18. Robinson (ed.), *A Symposium on Sterilization of the Unfit*, 20 MED. REV. OF REVIEWS 13 (1914).

19. *How Far Shall the Public School System Care for the Feeble-Minded?* 58 J.A.M.A. 1631, 1632 (1912).

20. *New Jersey's Rational Approach to the Problems of Degeneracy*, 20 MED. REV. OF REVIEWS 71 (1914).

21. *Care of the Feeble-Minded* (editorial), 89 MED. RECORD 827, 828 (1916).

22. Wildman, *Mental Defectives: Their Importance*, 88 MED. RECORD 1093 (1915).

23. *The Menace of the Feeble-Minded*, 62 J.A.M.A. 938 (1914).

remain in the public schools, "contaminating the rest of the school children by their . . . psychic insufficiency, moral indifference, and uncontrollable impulses."[24] Physicians advocated that all children be examined when they first entered school, so that those found to be feeble-minded could be excluded and segregated in institutions.[25] Once institutionalized, these children were to be segregated for life: To give the feeble-minded training and then "turn them loose on the community" would be "a moral and economic blunder."[26]

Physicians, both in the public health service and in private practice, played an important role in identifying candidates for institutionalization. Doctors were eager to arrogate this role to themselves, and feared that IQ tests would render their participation less essential. Physicians urged that retardation was "fundamentally a medical problem,"[27] and that physicians were best suited to diagnose it.[28] Because of the grave danger posed by the borderline retarded person,[29] an incorrect diagnosis of retardation could result in "untold danger"[30] to society. Physicians argued that it was often impossible for the lay person to make a diagnosis of retardation by inspection alone and that doctors were uniquely qualified to make the determination because of their expertise in the physical manifestations of inferior mentality (the so-called "stigmata of degeneration"): "It is only by close

24. Punton, *The Segregation and Treatment of the Feeble-minded*, 222 ILL. MED. J. 299 (1912).

25. *How Far Shall the Public School System Care For the Feeble-Minded?* *supra* note 19, at 1632 (statements of Drs. E. Bosworth McCready & W.G. Schauffler).

26. *The Feeble-Minded in Ohio*, 64 J.A.M.A. 1681 (1915). *See also* Spaulding, *Our Criminal Problem From The Standpoint of Classification and Segregation*, 173 BOSTON MED. & SURG. J. 527 (1915); Kendall, What Are We Doing and What Should We Do For the Feebleminded? (Paper given before the annual meeting of the Medical Association of the Southwest), *abstracted in* 65 J.A.M.A. 1845 (1915).

27. Schlapp & Paulsen, *Report on 10,000 Cases from the Clearinghouse for Mental Defectives*, 93 MED. RECORD 269 (1918).

28. Schlapp, *The Clearing House for Mental Defectives*, 88 MED. RECORD 299, 300 (1915).

29. *Care of the Feeble-Minded*, 89 MED. RECORD 827, 828 (1916).

30. Schlapp & Paulsen, *supra* note 27, at 301.

attention to details of physical makeup that the suspicion may be aroused that the subject is abnormal."[31]

Physicians recommended that medical personnel be given the authority to designate who should be committed. For example, in a report adopted by the New York Psychiatric Association, a committee of three physicians recommended that in each community a local health official be designated to act as "Medical Supervisor of the Mentally Defective," to arrange for the examination and placement of all persons brought to his attention who might be retarded.[32] In New York City, the trustees of the Post-Graduate Hospital set up a Clearing House for Mental Defectives staffed by ten physicians and four psychologists, charged with "scientific detention, diagnosis, registration of and research into mental deficiency." Its purpose was "to deal with the problem presented by the mentally unfit members of the community, in order that the most dangerous of them may be eliminated from among the possibilities of menace" and to ensure their "proper segregation."[33]

The private physician also played an important role in detecting feeble-minded persons and convincing their families of the need for segregation. A common lament in the medical literature of the Era was the difficulty physicians encountered in persuading parents to allow their children to be institutionalized. For example, Theodore Diller, a Pittsburgh physician, reported in a paper read before the Chicago Medical Society and the Academy of Medicine in Cleveland:

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31. Wildman, *supra* note 22, at 1093.

32. *Outline of a State Policy for Dealing With Mental Deficiency*, 87 MED. RECORD 665, 667 (1915). Two of the five members of the commission appointed in 1914 by the governor of New York to investigate the "problem" of the "feeble-minded" in that state were physicians and professors of medicine at leading medical schools in the state. 86 MED. RECORD 208 (1914).

33. Schlapp, *supra* note 28; Schlapp & Paulsen, *supra* note 27. Physicians were also assigned by school officials to examine and determine the status of children referred by teachers as suspected of having a mental or physical defect. *See, e.g.*, Krause, *The Necessity for Parental Cooperation in the Examination of Mental Defectives*, 86 MED. RECORD 337 (1914).

> "I have had numerous experiences where I have strongly advised that a feeble-minded child be sent to the institution at Polk for the good of the child, for the good of the parent, and for the good of the public, and where the parents have declined to take the step. Also, I have had the experience of seeing feeble-minded persons taken to an institution and brought away from it against the advice of the superintendent of the institution and myself. In short, this very important and fundamental question of admission or discharge from institutions for the feeble-minded is decided by the parents of the feeble-minded; and the institution or family physician have only advisory powers. This is obviously wrong and should be corrected."[34]

In a similar vein, a physician from Kansas City decried that feeble-minded children were allowed to "stay in school and mix with the other pupils" because of the "pride, indifference, financial and social standing or political pull" of their parents and complained,

> "Many such are referred to the family physician for relief, but what to do for them at once propounds the most difficult medical, legal, sociological problem of this age, because of the serious lack of state or civic provision, as well as the legal complications involved in enforcing their appropriate custody and control. Many parents refuse absolutely to cooperate with the authorities, hence a large number of such defective children are forced back on society and allowed to go more or less unrestrained."[35]

Nevertheless, commitment to eugenicism was not universal among the medical profession. Some physicians argued that the healer's traditional role was better served by searching out and

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34. Diller, *Menace to the Public by Feeble-minded Persons Living Outside Institutions*, 11 CLEVELAND MED. J. 420 (1912).

35. Punton, *supra* note 24, at 302. *See also* Bernstein, The Various Phases of Feeblemindedness and the Stigmata of Degeneration, Physical Types, etc. (Paper presented before the 11th Annual Meeting of the Medical Society of the State of New York), *abstracted in* 91 MED. RECORD 876 (1917).

alleviating possible physiological causes of retardation[36] than by rounding up retarded persons for segregation; others argued that marriage and the family should not be reduced to "breeding experiments"[37] and attacked the shoddy methodology of the geneology studies.[38] Indeed, physicians on both sides of the eugenics issue understood that there was an irreducible conflict between the healing function of the medical profession and the eugenicist's desire to improve the race. Eugenicists told physicians that it was their own "humanitarianism" that, by interfering with the survival of the fittest, had plunged the race into its present state of decline.[39] Physicians admitted the allegation. As one commentator, reporting for a medical journal on the first world Eugenic Conference held in London in July 1913, put it, in terms addressed to both physicians and parents:

> "Unfortunately, we are at present degenerating rather than progressing, because with our modern ideas of sanitation, good housing, proper medical treatment and the increase of comfort, we preserve inferior types which would have never reached maturity under the more severe conditions of even a century ago. The weeding out process which obtains among wild animals and preserves a highly vigorous type amongst them, no longer applies to civilized man and the more our sympathies go towards the helpless and diseased, the worse it is for the race. Let us therefore show interest in the eugenic movement; to do this, however, we must put aside our sympathies for the unfit. Women must help the men and, however repulsive it is to our refined feelings, we

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36. *Feeblemindedness as a Constitutional Anomaly*, 62 J.A.M.A. 304 (1914).

37. Groszmann, *Sane Eugenics*, 20 MED. REV. OF REVIEWS 638, 639 (1914).

38. *Id.* at 640. *See also Eugenics Laws*, 20 MED REV. OF REVIEWS 405, 406 (1914).

39. *See, e.g., The Problem of the Feeble-Minded* (editorial), 58 J.A.M.A. 785 (1912) (reporting eugenicist Charles Davenport's views).

must learn to understand that just as . . . animal experimentation entails some suffering, so the eugenic movement will mean severe repressive measures before it becomes effective."[40]

The issue whether handicapped infants should be allowed to die at birth posed the conflict between the healer's mission and the eugenicist's dream of a superior race most sharply. Physicians seldom discussed the issue in public, no doubt because they understood that such practices could carry both criminal and civil penalties.[41] In 1915, however, the highly-publicized case of John Bollinger, a handicapped infant born at the German-American Hospital in Chicago in 1915, whose life Dr. Harry Haiselden, Chief of Staff at the hospital, refused to save by performing surgery to correct an imperforate anus, thrust the issue into public attention.[42]

Two round-table discussions held shortly after the Bollinger incident illustrate the terms in which the conflict was posed between the physician's lifesaving duty and the eugenicist's perception of his duty to the race. At a "Symposium on Obstetrical Abnormalities" sponsored by the *Medical Review of Reviews*, a group of prominent obstetricians (all of whom had faculty appointments at university medical schools and medical colleges) discussed the question whether, when a severely handicapped baby is delivered, the obstetrician should neglect to tie the umbilical cord.[43] Partly because of the nature of the question (as several participants pointed out, a newborn will not usually die

40. Mason, *supra* note 7, at 148.

41. The *Journal of the American Medical Association* carried no discussion of the Bollinger case (*see infra* notes 42-63 and accompanying text) or any of the other widely-discussed cases of handicapped infants denied medical treatment during the Era. For the legal views of the Era, *see Is it a Crime For A Physician To Cause a Parent to Withhold a Life-Saving Operation or Remedy From a Dying Child?* 81 CENTRAL L.J. 379 (1915) (answering the question in the affirmative); *Editorial Comment*, 22 CASE & COMMENT 680 (accord).

42. *See* text of Brief, *supra* at pp. 9-10. For a general discussion of the Bollinger case, *see* S.L. Kuepper, Euthanasia in America (Rutgers Univ. diss. 1981), at 68-83.

43. *A Symposium on Obstetrical Abnormalities*, 22 MED. REV. OF REVIEWS 95 (1916).

from an untied umbilical cord) and their recognition that such an act would be unlawful, most responses were negative. Many participants echoed the statement of a professor at the University of Pittsburgh that such an act would be simply "contrary to medical ethics and all other forms of ethics."[44] Others added that "however much such an act might be in the interest of society or the development of the ideal,"[45] it would be an abuse of the physician's duty to heal.[46] Several respondents voiced the typically nineteenth-century attitude that a person's endowment could not be judged at birth[47] and that the presence of deformity should "stimulate . . . the medical investigator to find a means of restoring such individuals to health."[48] Other participants, however, stated that abnormalities are "a detriment to society" and that it is "humane to cut off their future suffering by one means or another, preferably 'forgetting' to tie the cord.[49] Another responded with regret that

> "the physician has no right under the laws, as they exist, to terminate the life of a new born infant . . . for no one shall be deprived of life — without due process of law. There exists at the present time no process of law by which this, however desirable, can be accomplished."[50]

He added, "The question is really an economic one and the ethical questions involved ultimately arise from economic facts," and suggested that the matter might be proposed for legislative discussion, but, until then, it was necessarily "academic."[51]

The round table on "The Defective Child" sponsored by the *Medical Standard*[52] evoked a different discussion. The journal invited not only Dr. Haiselden himself but also Dr. Henry H.

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44. *Id.* at 97 (statement of Dr. Walter L. Croll).
45. *Id.* at 100 (statement of Dr. Walter P. Manton).
46. *Id.* at 99 (statement of Dr. Nathan Jenks).
47. *Id.* at 100 (statement of Dr. Henry J.E. Newman).
48. *Id.* at 102 (statement of Dr. Herbert M. Stone).
49. *Id.* at 102 (statement of Dr. William C. Rausch); *id.* at 100 (statement of Dr. David Monash).
50. *Id.* at 97 (statement of Dr. Edward M. Colie, Jr.).
51. *Id.*
52. 39 MED. STANDARD 35 (1916).

Goddard, author of numerous works on eugenics and the dangers of retarded persons to society. A majority of the participants advocated the eugenic solution to the problem of the "defective" infant. Dr. Haiselden echoed nearly all the common sentiments of the eugenicist wing of the medical profession recited above. He declared himself willing to sacrifice the physician's duty to heal for the progress of the race. "The whole human race is deteriorating," he stated, "because of false ideas that saving human life is absolutely sacred."

> "We are bending our best energies to saving life which will in no way add to our prestige as a nation of eugenists or even of advanced ideas. In other words, by our hot house methods we are keeping alive disease which should be destroyed and would be destroyed if it were not for extraordinary efforts made to preserve it."

He summarized his views on the care of the defective child as follows:

> "The physician owes a duty to humanity, to the parents, and to himself to use no means other than supplying the necessary warmth and food to keep the child alive. Progress will in the near future . . . demand that he go one step farther and neglect to tie the cord."

As for "defective" children who survive, Dr. Haiselden thought they should be "cared for by the state in an institution and not be permitted to be at large. Such individuals are . . . a constant pain to their parents and relatives." Dr. Haiselden urged that defectives be sterilized immediately after they are placed in institutions, and went on to express his hope that "if all defectives were placed in institutions and the institutions were used to the best advantage of the eugenists," those who subscribed to his beliefs would be able to secure data that would convince the general public of the value of eugenics. He lamented that while "[t]hose of scientific training are readily convinced . . . the general public is inclined to hesitate."[53]

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53. *Id.* at 35-36.

Dr. Rose Alexander Bowers of Laporte, Indiana argued strongly that the law of "survival of the fittest" be allowed to govern the care of handicapped newborns and that the physician in charge should be allowed to decide the merits of each case. "As we weed out the undesirable growths in a garden, in the same manner we should prevent and destroy the defective seedlings in the human garden." The attitude of the state toward those who survive should be "one of suppression, no matter whether he be a mental or physical abnormal." Mental defectives needed to be sterilized and segregated for their own protection and that of society, "which is never edified by the sight of an idiot."[54]

Dr. Frederick H. Robinson of New York City stated that the lives of "imbeciles" should not be saved *even where* the parents "in sound mind and good economic position" demand it. "The physician's duty to humanity demands that he limit, not increase, the number of defectives" for "if present conditions continue unabated, the whole nation will be lowered in its vitality and will not be able to keep up the march of progress with other nations."

> "[T]he defective child is a burden and takes away what rightfully belongs to normal human beings. No special attempt should be made at any time during its life to preserve the defective. A physician removes a rotten part or diseased condition in a patient. In the same way, the state should remove the hopelessly defective, so that the rest may thrive better."[55]

In all, seven out of the ten participants in the symposium agreed that death was an acceptable solution in the case of the defective infant. The round table closed with a statement by Dr. Goddard that the physician is under an affirmative obligation *not* to save the defective child's life, for "part of the physician's moral obligation is to the community and he has no right to bring into the community a being that will always be a burden and a source of

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54. *Id.* at 36-37.
55. *Id.* at 37-38.

unhappiness and inefficiency."[56] Approximately three years earlier, Dr. Goddard had hinted at these views when he spoke to the Third Annual Meeting of the American Association for the Study and Prevention of Infant Mortality. Dr. Goddard suggested, in his remarks to the Association, that reduced infant mortality would have dangerous social consequences if it led to the survival of retarded persons:

> "A surprisingly large percentage of people are of such low mentality that they are incapable of living a normal life. They do not have enough judgment or intelligence to do those things that make for happiness and prosperity. . . . a large percentage of these children, if they live and grow up, will be mentally deficient, will always be a burden on society and more or less a burden to themselves. Therefore, when we keep these people alive, we are simply laying up trouble for ourselves and for these same children."

Recognizing that his audiences were committed to saving life and therefore probably would not accept elimination of the "unfit" at birth, Dr. Goddard offered a tradeoff: Eugenicists would accept, however reluctantly, that all severely disabled people not be eliminated at birth in exchange for adoption of the remainder of the eugenicists' program — sterilization and segregation — by those whose humanitarianism would not allow them to condone infanticide:

> "If our humanity will not allow us to let these children die as infants, our humanity certainly does not prevent us from insisting that they shall be the last of their race."[57]

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56. *Id.* at 41-42.

57. *Reported in* 59 J.A.M.A. 1645 (1912). A physician and editor of a medical journal of the Era also suggested that the eugenicist and the healer "could come to an agreement" on the subject of elimination of the unfit. Eugenicists would agree not to kill off the "weak and puny" if healers would agree to do their best "to prevent the bringing forth of undesirable specimens." Robinson, *Eugenics and the Limitation of Offspring* (editorial), 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 266, 269 (1913). Dr. Robinson had already professed his sympathy for involuntary euthanasia of the "gibbering idiot" who

In other discussion of the incident, both supporters and opponents of Dr. Haiselden's handling of the Bollinger case agreed that the decision to let the child die was not a medical but a sociological judgment. An editorial in the *Medical Record* criticized Dr. Haiselden and suggested that if the child's *medical* condition had warranted nontreatment, nontreatment might have been justified. However, the reason he gave to the world and Cook County for his abstention was "not a good one" because it lay outside the scope of medical judgment: "A doctor cannot say that an infant who is physically defective cannot grow up to be a useful member of society."[58] In an article in the *Medical Review of Reviews*, a noted journalist and social activist praised Dr. Haiselden precisely *because* he had refused to restrict himself to medical considerations in deciding whether or not to treat the child.

> "[T]he time is here when the progressive wing of the medical profession . . . itself takes the position that the opinions of economists, sociologists, social workers and social reformers generally are, if anything, more important in the consideration of such a problem as this than the opinions of mere doctors."

The author praised Haiselden for placing the good of the race ahead of the good of the individual. "It is good . . . when a Dr. Haiselden arises among us and rekindles that faith in the ultimate socializing of the individual for the greater glory of the race."[59] Finally, an editorial in the *Boston Medical and Surgical Journal* that took no position on the matter related the interest aroused by the Bollinger case to the "ever-increasing interest of the public in problems centering around the control of the defective element in society."[60]

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is "a great burden to those around him," a "curse and humiliation" to his relatives, but unfortunately, "prefers life to death." *Euthanasia* (editorial), *id.* at 85 (1913).

58. 88 MED. RECORD 925 (1915).

59. Block, *supra* note 8, at 122.

60. *Modern Euthanasia*, 173 BOSTON MED. & SURG. J. 1008 (1915).

At the Round Table on the Defective Child, Dr. Haiselden had expressed the hope that physicians would go "one step farther" than denial of life-saving medical treatment and "neglect to tie the cord." Two years later, Dr. Haiselden did just that to a baby girl born with microcephaly.[61] The lesson of the latter case, he proclaimed, was that "physicians will more and more take it upon themselves to decide at birth the fitness or unfitness of a child to live."[62] That this child's death, and that of others killed in that year, passed virtually without comment in the medical journals or the popular press[63] may be an index of its acceptability once the foundation of the regime of segregation had been more securely laid.

The entire purpose of the regime was elimination of handicapped persons — whether by segregating them from the rest of society, preventing them from propagating, or destroying their lives at birth. Thus it can be no surprise that physicians who participated in the regime, and whose attitudes were shaped by it, should choose to abandon the role of healer for the sake of eliminating the "unfit" at birth.

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61. Haiselden, *Regarding the Meter Baby of Chicago*, 23 MED. REV. OF REVIEWS 697 (1917). In fact, Dr. Haiselden went one step farther even than that; he first ligated the cord to allow his colleagues to inspect the baby, then untied it and allowed the baby to bleed to death from the navel. *Id*.

62. *Id*.

63. Kuepper, *supra* note 42, at 82.

APPENDIX B
COMPILATION OF CONGRESSIONAL HEARINGS AND REPORTS, 1972-1975

On the Rehabilitation Act of 1973 and the succeeding Rehabilitation Amendments of 1974, see during the 92d Cong., 2d Sess. (1972): *Vocational Rehabilitation Services for the Handicapped*, Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Rehabilitation Act of 1972*, Parts 1 & 2, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 92-928; S. REP. NO. 92-1135; H. CONF. REP. NO. 92-1581; during the 93d Cong., 1st Sess (1973): *Vocational Rehabilitation Services*, Parts 1 & 2, Oversight Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Rehabilitation Act, 1973*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 93-244; S. REP. NO. 93-318; H. CONF. REP. NO. 93-500; during the 93d Cong., 2d Sess. (1974): *Rehabilitation Act Amendments of 1974*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. REP. NO. 93-1048; S. REP. NO. 93-1139; H. CONF. REP. NO. 93-1457.

On the Developmentally Disabled Assistance and Bill of Rights Act of 1975, see during the 93d Cong., 1st Sess. (1973): *Developmental Disabilities Act Extension and Rights of Mentally Retarded, 1973*, Hearings on S. 427 and S. 458 Before the Subcomm. on Labor and Public Welfare; during the 93d Cong. 2d Sess. (1973): *Developmentally Disabled Assistance and Bill of Rights Act, 1974*, Hearings on S. 3378 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; *Health Services and Health Revenue Sharing*, Hearings on H. R. 11511, 11518, 11845 and 12892 Before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce, Part 2; S. REP. NO. 93-1169; H. R. REP. NO. 93-1127; during the 94th Cong., 1st Sess. (1975): *Developmentally Disabled Assistance and Bill of Rights Act,*

1975, Hearings on S. 462 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; *Health Services Programs*, Hearings on H. R. 2954 Before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce; S. REP. NO. 94-160, see especially the parts at 26-39, "Forces Behind Institutionalization and Deinstitutionalization" and "Bill of Rights for the Mentally Retarded and Other Individuals with Developmental Disabilities," which accompany Title II, the Bill of Rights; H. R. REP. NO. 94-58; H. CONF. REP. NO. 94-473.

On the Education for All Handicapped Children Act of 1975 and its predecessor Elementary and Secondary Education Amendments of 1974, see during the 93d Cong., 1st Sess. (1973): *Education of the Handicapped Act Amendments*, Hearings Before the Select Subcomm. on Education of the House Comm. On Education and Labor; *Education for the Handicapped, 1973*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; during the 93d Cong., 2d Sess. (1974): *Financial Assistance for Improved Educational Services for Handicapped Children*, Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Education for All Handicapped Children, 1973-74*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare, Parts 1-4; H. R. REP. NO. 93-805; S. REP. NO. 93-763; H. CONF. REP. NO. 93-1211; during the 94th Cong., 1st Sess. (1975): *Education for all Handicapped Children, 1975*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 94-332; S. REP. NO. 94-168; H. CONF. REP. NO. 94-664; S. CONF. REP. NO. 94-455.

On the White House Conference on Handicapped Individuals Act, see S. REP. NO. 92-1080, 92d Cong., 2d Sess. (1972); S. REP. NO. 93-319, 93d Cong., 1st Sess. (1973); S. REP. NO. 93-1139, 93d Cong., 2d Sess. 31-40 (1974).

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No. 84-1529

IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

vs.

AMERICAN HOSPITAL ASSOCIATION, et al.

Respondents.

ON A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF HON. ORRIN G. HATCH AND AUSTIN J. MURPHY, MEMBERS OF THE CONGRESS OF THE UNITED STATES, IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

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No. 84-1529

IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

vs.

AMERICAN HOSPITAL ASSOCIATION, et al.

Respondents.

ON A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF HON. ORRIN G. HATCH AND AUSTIN J. MURPHY, MEMBERS OF THE CONGRESS OF THE UNITED STATES, IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

NOTE

This Brief Amicus Curiae is filed with the consent of all parties to this appeal. A letter from each attorney stating this consent has been filed herewith with the Clerk of this Court.

STATEMENT OF INTEREST

The amici are members of the Congress of the United States who took an active role in formulating and sponsoring the Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1984 (hereinafter Child Abuse Amendments of 1984). Senator Orrin G. Hatch is the Chairman of the Senate Committee on Labor and Human Resources in which the bill was considered and amended before being recommended to the full Senate. In addition, Senator Hatch was the principle co-sponsor of consensus amendments negotiated and fully supported by a wide range of disability rights, right to life, medical and hospital groups which were incorporated into the Senate bill and adopted by Congress. Representative Austin J. Murphy was Chairman of the Subcommittee on Select Education of the House Committee on Education and Labor, which considered and amended the Child Abuse Amendments of 1984 before presenting them to the House, and was the principle House sponsor of the bill and proposed amendments to the bill on the floor which were adopted in the House. Senator Hatch and Representative Murphy were also members of the Joint Conference Committee which resolved the differences between the House and Senate versions of the bill and recommended the compromise bill which was ultimately passed by both bodies.

The amici are aware that an argument has been made before this Court that, because Congress provided for state protection of handicapped infants in the Child Abuse Amendments of 1984, Congress impliedly acquiesced in the lower courts' determination that Section 504 of the Rehabilitation Act of 1973 (hereinafter Section 504) was not intended to encompass medical treatment decisions for handicapped newborns and instead expressed its intent to approach the problem solely through state mechanisms. Because this argument misperceives the clear intent of Congress in the enactment of the Child Abuse Amend-

ments of 1984, the amici offer this brief to reaffirm Congressional intent that the passage of the Child Abuse Amendments of 1984 have no effect on any right or protection of disabled infants under Section 504.

BRIEF AMICUS CURIAE

NOTE

The Questions Presented and The Statement of the Case are omitted from this Amicus Curiae Brief since they are amply stated in the Appellant's Brief of Margaret M. Heckler.

SUMMARY OF ARGUMENT

The Bloomington, Indiana "Infant Doe" case abruptly brought to public awareness the problem of discrimination against severely disabled newborns in medical treatment decisions. The Department of Health and Human Services promptly took steps to implement a nondiscrimination policy under Section 504 of the Rehabilitation Act of 1973. At the same time, Congress considered legislation which would require states to implement federal policy protective of disabled newborns through state child abuse agencies. Congress' action culminated in the Child Abuse Amendments of 1984.

Aware of the controversy surrounding the HHS regulations under Section 504, Congress included in the Child Abuse Amendments a statutory construction provision clearly stating Congressional intent that the Child Abuse Amendments were not to be construed as affecting the federal protective role pursuant to Section 504. The legislative history of the provision indicates that Congress' intent on this point was unambiguous and consistent. Regardless, Respondents in the present case have argued to this Court that passage of the Child Abuse Amendments evinced Congressional intent to ratify the lower federal courts' interpretation of Section 504 and to prescribe a

limited federal role in the protection of disabled infants. The argument is contrary to Congress' clearly expressed intention.

Moreover, the circumstances surrounding the passage of the Child Abuse Amendments of 1984 do not warrant an inference of Congressional ratification of judicial decisions construing Section 504. A fair examination of the Amendments themselves indicates that their scope is separate from and complementary to Section 504. This Court's decisions have shown that a deferential and cautious approach is required when the judiciary attempts to ascertain from subsequent conduct Congress' intent with regard to prior legislation. The contrary approach urged by Respondents would irrevocably shift the balance of power away from Congress to the lower federal courts.

ARGUMENT

I

CONGRESS' INTENT IN PASSING THE CHILD ABUSE AMENDMENTS OF 1984 WAS TO ENSURE STATE INVOLVEMENT IN THE PROTECTION OF HANDICAPPED NEWBORNS WITHOUT LIMITING THE FEDERAL PROTECTIVE ROLE PURSUANT TO SECTION 504 OF THE REHABILITATION ACT OF 1973.

A. Congress Perceived Discrimination Against Handicapped Newborns in Medical Treatment Decisions as a Serious Problem and It Enacted Significant Provisions of the Child Abuse Amendents of 1984 In Order to Involve the States in Addressing That Problem.

On April 9, 1982, a child was born in Bloomington, Indiana with Down's Syndrome and a surgically correctable esophageal blockage which prevented food ingestion. The parents and their obstetrician decided to withhold beneficial surgery as well as intravenous feeding from the

child because of the child's prospects for mental retardation. Six days later, the child, known as Infant Doe, died of starvation and dehydration, despite attempts to obtain a court order for treatment.[1]

The death of Infant Doe resulted in considerable press and Congressional attention, much of it critical of the denial of treatment. See Editorial, *The Bloomington Baby*, Washington Post, April 18, 1982, at 23; Editorial, *"Private" Death*, N. Y. Times, April 27, 1982, at A22; 128 *Cong.Rec.* H1489-90 (daily ed. April 20, 1982) (statement of Rep. Hyde). On April 30, 1982, President Reagan sent a memorandum to the Attorney General and the Secretary of Health and Human Services (HHS) citing the *Infant Doe* case, noting federal law prohibits discrimination against the handicapped and requiring the Secretary and Attorney General to take action to avoid a reoccurrence of the *Infant Doe* incident. *See* 48 Fed.Reg. 9630 (1983). This Presidential directive set into motion a series of events which resulted in the promulgation by HHS of the Final Rules under Section 504, 49 Fed.Reg. 1622 (1984), which are the subject of this appeal.

While the executive branch of the United States government was reacting to the public outcry over Baby Doe and putting into place specific federal protection for disabled infants under Section 504, Congress was considering its response. On May 26, 1982, Representative John Erlenborn introduced H.R. 6492, a bill to amend the Child Abuse Prevention and Treatment Act to protect handicapped infants "against attempts to cause their death through denial of nutritional sustenance or medical treatment routinely provided to other handicapped or non-handicapped individuals." 128 CONG.REC. E2490 (daily ed. May 26, 1982) (Remarks of Rep. Erlenborn). On March 3,

[1] For a full recitation of the facts of the case of Infant Doe and the efforts made to obtain a court order for treatment, *see* Petition for Writ of Certiorari, *Infant Doe v. Bloomington Hospital*, No. 83-437, *cert. denied*, 104 S.Ct. 394 (1983).

1983, in the 98th Congress, Rep. Murphy, amicus curiae herein, introduced H.R. 1904, which served as the genesis for a series of Congressional hearings followed by committee and floor action which culminated in the Child Abuse Amendments of 1984. Pub.L. 98-457, tit. I, secs. 121-28, 98 Stat. 1749 (codified at 42 U.S.C. §§ 5101 to 5103. The final version of the Child Abuse Amendments of 1984 was hammered out in marathon negotiations in the spring and summer of 1984 among representatives of disability groups, medical and hospital associations, right to life organizations, and a bipartisan group of Senators whose views span the ideological spectrum. *See* 130 CONG.REC. S8952-53, 8955-56 (daily ed. June 29, 1984) (remarks of Senators Hatch, Cranston, Dodd, Denton, and Nickles). On October 9, 1984, President Reagan signed the bill into law to take effect on the same date in 1985.

Both Congressional committees which considered the Child Abuse Amendments of 1984 were concerned about the reported incidents of handicapped infants being "denied medical treatment for life-threatening conditions, whereas infants who are not handicapped, but do have similar life-threatening conditions have received medical treatment," and intended to ensure by these provisions that "these infants are not denied medically indicated treatment due to their handicap." HOUSE COMM. ON EDUCATION AND LABOR, CHILD ABUSE AMENDMENTS OF 1983, H. REP. NO. 159, 98th Cong., 1st Sess. 2 (1983); SENATE COMM. ON LABOR AND HUMAN RESOURCES, CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT AMENDMENTS OF 1983, S.REP.NO. 246, 98th Cong., 1st Sess. 16 (1983). As a result of hearings on the bill, CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT AMENDMENTS OF 1983: HEARINGS BEFORE THE SUBCOMM. ON FAMILY AND HUMAN SERVICES OF THE SENATE COMM. ON LABOR AND HUMAN RESOURCES, 98th Cong., 1st Sess. (1983), the Senate Committee found that the inappropriate denial of medical care to infants on the basis of handicap was not limited "to one or two instances." SENATE REPORT,

at 16. All witnesses before the Senate Subcommittee agreed that "there is a sufficient body of evidence that such cases do occur and that it is an issue that needs greater scrutiny and remedial action." *Id.* at 11. As a result of these findings, the Senate Committee concluded that, if physicians are acting upon their convictions as reported in several surveys of physicians and as exemplified by highly publicized cases, "then federal policy on the civil rights of handicapped persons, is being contravened." *Id.* at 9.

Spurred by its findings of discriminatory denial of beneficial medical care to disabled infants, Congress included significant provisions in the Child Abuse Amendments of 1984 to involve the states in protecting handicapped infants in need of medical treatment.[2] In general, the Act now requires states that receive federal funds for their child abuse and neglect agencies to regard withholding of medically indicated treatment from disabled infants with life-threatening conditions as a form of child neglect. States must require prompt notification of suspected instances of such withholdings by individuals designated by each health care facility, and provide for the pursuit of legal remedies by state child protective service agencies as needed to prevent such withholding. The Act establishes grants to improve the provision of services for disabled infants with life-threatening conditions and for national and regional clearinghouses to provide current information about medical and community resources to assist such children. It requires HHS to issue regulations to implement the Act and to publish model guidelines (with no mandatory force) for hospital based Infant Care Review Committees.

By specifically including disabled infants with life-threatening conditions as children to be protected by state child abuse agencies, Congress intended that state

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[2] The text of the Child Abuse Amendments of 1984 is set forth in the Appendix to Respondents' [American Hospital Association, *et al.*] Brief in Opposition to Petition for Writ of Certiorari, herein.

resources and expertise be marshalled to implement federal policy protective of handicapped newborns. There is no implication, however, that the specific state actions mandated by the Child Abuse Amendments of 1984 were intended to be the exclusive channels of federal protection for handicapped infants or that the Amendments were meant to undercut any effort under Section 504. Rather, a two-pronged approach to the discrimination problem can be seen: one prong uses state child protection mechanisms, and the other prong uses federal enforcement machinery directed at health care providers receiving federal financial aid.

B. Congress Intended That No Provision of the Child Abuse Amendments of 1984 Would Affect Any Right or Protection Afforded Handicapped Infants Under Section 504 of the Rehabilitation Act of 1973.

Respondents American Hospital Association and American Medical Association claim that the passage of the Child Abuse Amendments of 1985 was intended by Congress to "reject on policy grounds the direct federal role adopted solely by the Secretary in her 504 regulations." Brief of the Respondents American Medical Association, *et al.*, in Opposition at 26, herein. *See also* Respondents' [American Hospital Association, *et al.*] Brief in Opposition to Petition for Writ of Certiorari at 14-15, herein. In addition, Respondents AHA and AMA, as well as the Respondents' amicus curiae American Academy of Pediatrics, claim that the failure of Congress to amend Section 504 in light of the *University Hospital* case[3] and instead to pass the Child Abuse Amendments of 1984 "clearly addressed the question of what federal response was appropriate with respect to the tragic question of providing appropriate treatment to severely impaired newborns." AMA Brief at 26. *See also* AHA Brief at 14-15; Brief for Amicus Curiae American

[3] United States v. University Hospital, 575 F.Supp. 607 (E.D.N.Y. 1983) *aff'd.*, 729 F.2d 144 (2d Cir. 1984) (holding that Congress did not intend Section 504 to encompass medical treatment decisions).

Academy of Pediatrics in Opposition to a Petition for Writ of Certiorari at 16-17, herein.

The claim that the passage of the Child Abuse Amendments of 1984 demonstrates Congressional hostility toward protection of disabled infants under Section 504 is fundamentally erroneous. The statutory construction provision included in the Amendments and the legislative history of the Amendments evince an altogether different intent.

1. Congress Expressed Its Intent That the Child Abuse Amendments of 1984 Have No Effect On Section 504 Rights in an Explicit Statutory Construction Provision.

Congress was aware of the efforts of HHS to enforce regulations under Section 504 to protect disabled infants and of the pending federal court cases on the validity of the Section 504 regulations when it considered and adopted the Child Abuse Amendments of 1984. As a result, Congress sought to ensure that the passage of the Child Abuse Amendments of 1984 would not be construed as precluding federal protection of handicapped infants under Section 504 or as ratifying the *University Hospital* case. In an exercise of caution, Congress adopted, *as part of the Child Abuse Amendments of 1984 themselves*, the following provision on statutory construction:

> Sec. 127(a) No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

Child Abuse Amendments of 1984, Pub. L. 98-457, tit. I, sec. 127(a). This provision emphatically and unambiguously states the intent of Congress in adopting the Amendments and precludes any construction of the Child

Abuse Amendments of 1984 as limiting or lessening any right of protection under Section 504 for disabled infants.[4]

2. The Legislative History of the Child Abuse Amendments of 1984 Confirms Congress' Intent That the Amendments and Section 504 Be Viewed Separately.

The legislative nistory of the Child Abuse Amendments of 1984 reflects a consistent intent of Congress to ensure that the passage of the Child Abuse Amendments of 1984 would not be interpreted to limit any right or protection for handicapped infants under Section 504.

The original amended bill was submitted to the full House on May 16, 1983, by the Committee on Education and Labor with the following provision on statutory construction:

> Sec. 8. No provision of this Act may be so construed as to limit or lessen any right or protection under Section 504 of the Rehabilitation Act of 1973.

HOUSE REPORT, *supra*, at 27. The House Committee report included an explanatory statement which explained the inclusion of this provision:

> [T]he Committee intends to have the Secretary of HHS provide technical assistance and training to encourage and assist the States in developing and implementing new procedures or improving present procedures to be followed by child protective service agencies ... and courts of competent jurisdiction for the purpose of insuring that the specified treatment in this Act (including services assured under the provisions of section 504 of the Rehabilitation Act of 1973)

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[4] Amici note that Respondents made reference to Section 127(a) of the Act only by reference in a footnote, AMA Brief, *supra*, at 26 n.26; AHA Brief, *supra*, at 15 n.9, while claiming that Congress intended to preclude federal protection under Section 504 when adopting the Child Abuse Amendments of 1984.

> is provided for infants at risk with life-threatening congenital impairments.

HOUSE REPORT, *supra*, at 3.

The intent of this provision and the interaction between the Child Abuse Amendments of 1984 and Section 504 were addressed during the February 2, 1984, House floor debate on the bill. Rep. Murphy, floor manager for the bill and amicus curiae herein, stated:

> Finally, the bill reaffirms the civil rights of all children to have an opportunity to live without fear of being denied the necessities of life. This includes section 504 of the Rehabilitation Act of 1973 which applies to handicapped persons.

130 CONG.REC. H379 (daily ed. Feb. 2, 1984). Representative Murphy also inserted into the record an article written by him to explain the bill, in which he said:

> The bill simply reaffirms two principles under current law.... The second reaffirmation concerns Section 504 civil rights as they apply to the infants. Withholding of treatment is not automatically acceptable simply because the child is handicapped. The child is protected the first second after birth through the last second of life. Again, the right to life traditionally outweighs anyone's interpretation of a minimally acceptable quality of life. Even the U.S. Commission on Civil Rights in its report, "Accommodating the Spectrum of Individual Abilities" (Clearing-house Publication 81), recently recognized such cases as involving violations of handicapped citizens' civil rights.

130 CONG.REC. H380 (daily ed. Feb. 2, 1984).

Representative John Erlenborn, a cosponsor of the bill, also rose to explain the major provisions of H.R. 1904. He emphasized:

> H.R. 1904, as reported, would —
>
> * * *

> Sixth, state unequivocally that "no provision in this act may be so construed as to limit or lessen any right or protection under section 504 of the Rehabilitation Act of 1973...."

130 CONG.REC. H381 (daily ed. Feb. 2, 1984). Representative Erlenborn went on to comment on the HHS regulations promulgated pursuant to Section 504 and to applaud the Secretary and the Department for their efforts in addressing the issue of medical treatment for handicapped infants. He then noted the susceptibility of such regulations to shifting interpretations by changing administrations, and commented:

> In my view, Congress has a clear and necessary responsibility to establish public policy by taking timely and appropriate legislative action. We cannot abrogate this responsibility by acquiescing to a body of regulations with which we may agree today. Our obligation goes well beyond that. We have a responsibility to participate actively in the development of difficult public policy by taking positive statutory or legislative action. I believe that H.R. 1904 represents such a timely and positive step forward to the end that the rights of severely handicapped infants are more fully protected. I firmly believe that H.R. 1904 will provide a complimentary statutory basis for the HHS regulatory initiative developed under section 504 of the Rehabilitation Act.

130 CONG.REC. H382 (daily ed. Feb. 2, 1984).

The point was made again by Representative Steve Bartlett, a member of the Subcommittee which amended and reported out the bill:

> The intent of the new Infant Doe in H.R. 1904 affirms simply and unequivocably that such infants are to be afforded the same right to live that is guaranteed to an individual of any age with or without a handicapping condition.

> These are rights and protections already guaranteed by section 504 of the Rehabilitation Act and other laws of this Nation and the 50 States.

130 CONG.REC. H382 (daily ed. Feb. 2, 1984).

Even those who sought to amend the bill to substantially weaken its protections understood that the Child Abuse Amendments of 1984 were not intended to limit protection under Section 504. In the course of his remarks supporting the Chandler Amendment (which was not adopted), Rep. Waxman stated:

> This amendment is not about the controversial regulations that have been much publicized at the Department of Health and Human Services that various medical and hospital and disability groups have been working on. Those regulations are based on a completely different statute. Those regulations are based on the Rehabilitation Act and make provisions that affect another section of the law.
>
> I do not mean to support or oppose regulations at this time. They will stand or fall on their own merits, but they are not before this House today.
>
> The Chandler amendment is also not an attempt to address the complicated issues of section 504 of the Rehabilitation Act. As you will note, H.R. 1904 contains clear language saying that this bill is not to be used to limit any protection of that act.
>
> The Chandler amendment does not amend that portion of H.R. 1904 and would not affect the legal status of section 504 in any way.

130 CONG.REC. H396 (daily ed. Feb. 2, 1984).

Thus, the House devoted considerable attention to the possible effect of the Child Abuse Amendments of 1984 on federal protection under Section 504. The House clearly intended that the Child Abuse Amendments not limit any protection under Section 504. In fact, the House perceived

the Amendments to be consistent with and complementary to the Section 504 regulations.

Similar consideration of the effect of the Child Abuse Amendments of 1984 on Section 504 is reflected in the Senate consideration of H.R. 1904. The original Senate bill, S. 1003, approved by the Committee on Labor and Human Resources, did not contain any statutory construction provision similar to Section 8 in the House bill. Even at that time, however, the report from the Committee on Labor and Human Resources, which accompanied the bill, informed the Senate that:

> No provision of S. 1003 may be so construed to limit or lessen any right or protection under Section 504 of the Rehabilitation Act of 1973.

SENATE REPORT, *supra*, at 17.

On June 29, 1984, Senator Hatch, amicus curiae herein, for himself and five other principal cosponsors, introduced an amendment to S. 1003. The amendment included the following revised language of the statutory construction provision which was eventually adopted by both Houses:

> Sec. 205. (a) No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

130 CONG.REC. S8952 (daily ed. June 29, 1984). Accompanying the amendment was a "Joint Explanatory Statement by Principal Sponsors of Compromise Amendment Regarding Services and Treatment for Disabled Infants." The authors set forth the purpose of the statement:

> This explanatory statement is a product of the six principal sponsors of this compromise measure: Senators Hatch, Dodd, Denton, Cranston, Nickles, and Kassebaum. It is their intention that this statement serve in lieu of a Committee report on the compromise agreement and thus be the definitive legislative history in the Senate on it.

130 CONG.REC. S8953 (daily ed. June 29, 1984). This statement included a paragraph calling attention to and emphasizing the statutory construction provision:

> The amendment (in section 205) would provide that no provision of or any amendment made by the Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973.

130 CONG.REC. S8952 (daily ed. June 29, 1984).

As Senator Hatch explained on the Senate floor, the amendment was the product of detailed study and lengthy negotiations with numerous representatives of divergent views on the regulation of medical care decisions for handicapped newborns. The American Hospital Association, American Academy of Pediatrics, and the American Medical Association participated in the negotiations which led up to the consensus amendment. On June 19, 1984, the medical/hospital groups proposed a revision of the statutory construction provision of the House bill to provide that "no provision of the bill may be so construed as to *grant*, limit or lessen any right or protection under Section 504 of the Rehabilitation Act of 1973." The medical/hospital groups were concerned that the Child Abuse Amendments of 1984 would *reinforce* and *affirm* Congress' intent that disabled children were protected under Section 504. As a compromise in the negotiations, it was agreed that the Child Abuse Amendments of 1984 should be *neutral* on Section 504, and thus the final wording that no provision "is intended to affect any right or protection under Section 504" was agreed to. Senator Hatch listed for the Senate some nineteen medical, hospital, disability rights, and pro-life organizations among the participants at the negotiating table who joined in endorsing the proposed amendment. Included in that list is Respondent American Hospital Association and amicus curiae American Academy of Pediatrics, who now assert that Congress was hostile to Section 504 protection for disabled infants when it adopted the Child Abuse Amendments of 1984.

After passage of H.R. 1904 by the House and S. 1003 by the Senate, a Joint Conference Committee of both Houses met to resolve the differences in the House and Senate versions of the bill. The House receded from wording of the statutory construction provision and accepted the Senate version which was part of the Senate consensus amendment. CONFERENCE REPORT, CHILD ABUSE AMENDMENTS OF 1984, H. REP. NO. 1038, 98th Cong., 2d Sess. 25 (1984). On Sept. 26, 1984 and Sept. 28, 1984, the House and Senate respectively adopted the Conference Report. Before the adoption of the Conference Report by the Senate, a letter from Senators Hatch, Denton, Nickles, Kassebaum, Dodd and Cranston to Senator Weicker was entered in the record by Sen. Hatch to clarify Congressional intent behind the Child Abuse Amendments of 1984. The letter stated:

> S. 1003 was designed to address situations of withholding of medical treatment to disabled infants by relying upon existing state child protective services systems. Throughout the statutory language and accompanying explanatory material, we refer to authority under state law as the mechanism for pursuing legal remedies under our amendment. This legislation does not itself authorize direct federal involvement in individual cases.
>
> An important element of this compromise was that S. 1003 is neutral with regard to the on-going controversy over the applicability of a federal remedy to Baby Doe situations under section 504 of the Rehabilitation Act of 1973. This policy of neutrality is expressly set forth in section 205(a). . . .

130 CONG.REC. S12, 392 (daily ed. Sept. 28, 1984) (remarks of Sen. Hatch).

The amici take this opportunity to affirm the intent expressed in the legislative history that the Child Abuse

Amendments of 1984 be viewed independently of the Section 504 controversy.[5]

II

THE PRINCIPLES OF STATUTORY CONSTRUCTION PREVIOUSLY APPLIED BY THIS COURT SUPPORT THE CONCLUSION THAT THE CHILD ABUSE AMENDMENTS OF 1984 DO NOT EVINCE ANY CONGRESSIONAL INTENT TO LIMIT THE SCOPE OF SECTION 504 OF THE REHABILITATION ACT OF 1973.

The forthright legislative history of the Child Abuse Amendments of 1984 reveals that Congress deliberately refrained from addressing the scope of Section 504 in the child abuse legislation geared toward state action. Yet even apart from that history, your amici respectfully submit that logical principles of statutory construction applied by this Court would compel a conclusion that the Child Abuse Amendments of 1984 are not an expression of Congressional intent regarding the scope of Section 504.

The assertion by the Respondents herein that Congress intended the Child Abuse Amendments of 1984 to be its exclusive legislative action to protect handicapped infants appears to rest on the premise that, because Congress did not amend Section 504 but instead enacted a different piece of legislation dealing with the same subject as the Section 504 regulations in controversy, it was thereby acquiescing in the lower federal courts' determination that those regulations are outside the scope of Section 504 and invalid. The logic of this assertion is flawed in two respects.

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[5] The *amici* are cognizant of the respect paid by this Court to explanatory statements by members of a Committee reporting on a bill in Congress, as exemplified in *Sioux Tribe v. United States*, 316 U.S. 317, 329-30 (1941). There this Court said of a Senate Committee Report, which characterized as erroneous an interpretation of prior legislation, "[t]his statement by the Committee which reported the [prior Act], made within five years of its passage, is virtually conclusive as to the significance of that Act." Likewise, in *Pipefitters v. United States*, 407 U.S. 385, 409 (1972), this Court accorded "great weight" to the viewpoint of a sponsoring Senator concerning the scope of a bill, expressed during debate on the Senate floor.

First, your *amici* submit that the fact that Congress took no action during the few months following a lower court decision construing legislation cannot be interpreted as Congressional ratification of that court's interpretation. A lower court's construction of legislation is not definitive, particularly in a controversial area where an appeal is virtually certain. Moreover, even if the lower court decision were regarded as significant, the slow pace of the legislative machinery nearly precludes any significant action in so short a time.

This Court considered whether Congress had acquiesced in judicial statutory construction in *Blue Chip Stamps v. Manor Drug Stores*, 421 U.S. 723 (1975). In that case, the plaintiff claimed standing as a potential purchaser of stock to bring a private damage action under § 10(b) of the Securities Exchange Act of 1934, 48 Stat. 881. The federal courts had previously ruled that Congress intended to extend protection under § 10(b) only to actual purchasers and sellers of securities. This Court found in an opinion by Justice Rehnquist that Congress had ratified the federal courts' limiting interpretation, but only after noting that the interpretation had been consistently applied for over twenty years and that Congress had rejected two attempts to amend § 10(b) to expand its scope.

In the instant case, when the House adopted its version of the Child Abuse Amendments of 1984 on February 2, 1984, the only lower federal court decision on the applicability of Section 504 to disabled infants was found in *United States v. University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983), where the District Court, on November 17, 1983, had denied HHS's demand for the hospital records of Baby Jane Doe. That decision was on appeal. Between House passage of H.R. 1904 and its adoption by Congress, the Second Circuit Court of Appeals affirmed the District Court in *United States v. University Hospital*, 729 F.2d 144 (1984),

and the District Court herein had enjoined the Section 504 regulations. *American Hospital Association v. Heckler*, 585 F.Supp. 541 (S.D.N.Y. 1984). The Second Circuit decision on the Section 504 regulations was not handed down until *after the Child Abuse Amendments of 1984 were signed into law. Heckler v. American Hospital Association*, No. 84-6211 (2d Cir., Dec. 27, 1984). Thus, there were only eleven months, one court of appeals decision, and no unsuccessful attempts to amend Section 504 regarding this matter, between the first judicial construction of Section 504 and the passage of the Child Abuse Amendments of 1984. In addition, the matter was still being actively litigated in the federal courts. No reasonable construction of Congressional intent would equate this history with Congressional acquiescence in the judicial construction of Section 504.

Second, the fact that Congress has enacted a separate piece of legislation touching upon the same subject as prior legislation does not support an inference that Congress deems the prior legislation no longer applicable. This Court has unequivocably stated otherwise:

> It is a cardinal principle of construction that repeals by implication are not favored. When there are two acts upon the same subject, the rule is to give effect to both if possible. The intention of the legislature to repeal "must be clear and manifest." It is not sufficient "to establish that subsequent laws cover some or even all of the cases provided for by [the prior act]; for they may be merely affirmative, or cumulative, or auxiliary." There must be "a positive repugnancy between the provisions of the new law, and those of the old; and even then the old law is repealed by implication only *pro tanto* to the extent of the repugnancy."

United States v. Borden Co., 308 U.S. 188, 198-99 (1939) (citations omitted).

In *Jones v. Alfred H. Mayer Co.*, 392 U.S. 409 (1968), this Court considered the bearing of Congressional passage of the Fair Housing Title of the Civil Rights Act of 1968, Pub.L. 90-284, 82 Stat. 81, on the intended scope of 42 U.S.C. § 1982. The posture of that case in terms of the question of Congressional intent was remarkably similar to the present case. The old law, § 1982, extended general protection against racial discrimination in the sale and rental of property; the new Civil Rights Act provided in detail for federal machinery for the enforcement of such rights. In addition, the new Act contained a provision, § 815, which provided that "(n)othing in this title shall be construed to invalidate or limit any law of ... any ... jurisdiction in which this title shall be effective, that grants, guarantees, or protects the ... rights ... granted by this title...." The legislative history of the new Act, examined closely by the Court, showed that Congress was aware that a decision on the scope of § 1982 was pending before this Court, and that the scope might well be as broad as the petitioners there urged. The Court noted:

> On April 10, 1968, Representative Kelly of New York focused the attention of the House upon the present case and its possible significance. She described the background of this litigation, recited the text of § 1982, and then added:
>
> > "When the Attorney General was asked in court about the effect of the old law [§ 1982] as compared with the pending litigation which is being considered on the House floor today, he said that the scope was somewhat different, the remedies and procedures were different, and that the new law was still quite necessary."
>
> Later the same day, the House passed the Civil Rights Act of 1968. Its enactment had no effect upon § 1982 and no effect upon this litigation, but it underscored the vast differences between, on the one hand, a general statute applicable only to racial discrimina-

> tion in the rental and sale of property and enforceable only by private parties acting on their own initiative, and, on the other hand, a detailed housing law, applicable to a broad range of discriminatory practices and enforceable by a complete arsenal of federal authority.

392 U.S. at 416-17 (footnotes omitted). The Court also confirmed the Attorney General's view that the two statutes "stand independently":

> The Civil Rights Act of 1968 does not mention 42 U.S.C. § 1982, and we cannot assume that Congress intended to effect any change, either substantive or procedural, in the prior statute.

Id. at 416 n. 20.

Just as the Civil Rights Act of 1968 was found to enhance the protection of § 1982, the "Baby Doe" provisions of the Child Abuse Amendments of 1984 can only be seen as complementary to and consistent with Section 504, and not as a declaration that no rights under Section 504 exist. Here also, "the scope [is] somewhat different, the remedies and procedures [are] different, and ... the new law [is] still quite necessary." *Id.* at 416.

Some of the limitations of the Child Abuse Amendments of 1984 underscore the difference in scope between that Act and Section 504. First, the Child Abuse Amendments of 1984 only involve protection under state child abuse laws, while Section 504 involves substantial federal substantive law protection as well as federal enforcement machinery. Second, several states do not receive child abuse grants and thus need not comply with the Act and regulations while Section 504 applies to every recipient of federal financial assistance. Third, only child abuse agencies are required to act to protect disabled infants in these circumstances. Under Section 504, however, both the federal government and parents, who are often also victims of physician dis-

crimination in this area[6], are authorized to bring an action to protect their child. Fourth, the Child Abuse Amendments of 1984 only protect the rights of a child then alive and in need of medical treatment. If the child is dead or so debilitated by medical neglect that medical treatment is no longer beneficial, the Child Abuse Amendments of 1984 provide no remedy for the child or his parents — only termination of federal funds to the child abuse and neglect agency. In contrast, Section 504 allows a private damage action to compensate victims of discrimination. Fifth, the Child Abuse Amendments of 1984 deal with denial of treatment only on a case by case basis, and are ineffective against an institutionally adopted policy of discrimination. Section 504, however, may be enforced by injunctive actions which can protect a whole class of individuals from discrimination. Thus, no fair reading of the Child Abuse Amendments of 1984 would support the argument that Congress intended to preclude protection of disabled infants under Section 504.

In addition, giving effect to Respondents' argument that the enactment of the Child Abuse Amendments of 1984 indicated Congressional acquiescence in a lower federal court interpretation of Section 504 would unreasonably burden the Congress and would irrevocably change the balance between the judicial and legislative branches. Each time that Congress reconsiders a subject and legislates on it, all previous legislation on that subject would have to be reaffirmed. Congress would have to monitor every lower federal court decision and rush to amend federal law after each faulty lower court interpretation. These far-reaching and detrimental consequences would wreck havoc on the legislative function and irrevocably shift the balance of power away from Congress to the lower federal courts.

---

[6] See *Brief Amicus Curiae of Carlton Johnson*, herein, for a detailed account of a child and his mother who were victims of discrimination by physicians regarding medical treatment.

CONCLUSION

A fair reading of the statutory construction provision of the Child Abuse Amendments of 1984, an examination of the legislative history of that provision, and an application of this Court's principles in determining Congressional intent regarding separate legislation on similar subject matter, all point to the fact that Congress intended that the Child Abuse Amendments of 1984 have no limiting effect on the Section 504 rights of handicapped newborns.

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

---

BRIEF OF AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS, AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR THE DEVELOPMENTALLY DISABLED, NATIONAL REHABILITATION ASSOCIATION AS *AMICI CURIAE* IN SUPPORT OF PETITIONER

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IN THE

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v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF OF *AMICI CURIAE* AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, *et al.* IN SUPPORT OF PETITIONER

INTEREST OF *AMICI CURIAE*

Amici curiae are organizations of professionals who provide services, including health care, to mentally and physically handicapped people.

THE AMERICAN ASSOCIATION ON MENTAL DEFICIENCY (AAMD) is the nation's oldest and largest interdisciplinary organization of professionals in the field of mental retardation. Its members include physicians, educators, psychologists, social workers, nurses, physical and occupational therapists, specialists in communication disorders, administrators, and other professionals who serve people with mental retardation. AAMD

formally opposed the withholding of treatment on the basis of handicap as early at 1973.

THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS (TASH) (formerly the American Association for the Education of the Severely/Profoundly Handicapped) was founded in 1974 to develop, advocate, and implement federal statutes benefitting severely and profoundly handicapped individuals. TASH now has more than five thousand members, who include parents, physicians, educators, therapists, and other professionals. TASH has been directly involved in the issue of medical care and treatment for handicapped children. *See Legal, Economic, Psychological and Moral Considerations on the Practice of Withholding Medical Treatment from Infants with Congenital Defects* (TASH Monograph #1, 1984).

THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR THE DEVELOPMENTALLY DISABLED (AAUAP) is a national organization of university-based research, training, and model demonstration programs in the field of mental retardation. These programs employ professionals who represent all disciplines in the field of mental retardation and, among other activities, provide or assist in the provision of community-based educational, residential, vocational and health care services to people who are mentally retarded. AAUAP, along with AAMD, TASH, and other professional and voluntary organizations, is a signatory to the *Joint Policy Statement on Principles of Treatment of Disabled Infants*, which is included in the Appendix to this brief.

THE NATIONAL REHABILITATION ASSOCIATION (NRA) is one of the world's largest organizations of professionals, consumers, and other individuals devoted to improving the lives of handicapped children and adults. Founded in 1925, it has 20,000 members, the majority of whom are professionals serving physically

disabled people. The NRA has long worked for the development of programs and services that promote economic independence for the millions of persons with disabilities in this country.

The disability professionals who constitute the membership of *Amici* organizations provide mentally and physically handicapped individuals with a variety of services, including educational and medical services, and thus have abundant direct experience in this area. *Amici* wish to provide the Court with relevant information from the professional literature about recent advances in habilitation and other services for handicapped individuals and about the process by which decisions are made about medical care and treatment for newborn babies known or believed to be handicapped. The research findings and professional experience of members of *Amici* organizations support the position of Petitioner that civil rights enforcement is both appropriate and necessary to eliminate life-threatening discrimination on the basis of handicap.

The Petitioner and Respondents in this case have consented to the filing of this brief.

SUMMARY OF ARGUMENT

This case presents the narrow question of whether § 504 of the Vocational Rehabilitation Act prohibits the discriminatory withholding of appropriate medical care and treatment from newborn babies solely on the basis of their handicaps. In order to resolve this issue, it is necessary to understand the context in which Congress enacted § 504. It is also important to explore some of the contours of the debate over treating handicapped children in order to evaluate Respondents' contention that this particular form of discrimination is beyond the reach of the federal statute.

In enacting this anti-discrimination law, Congress affirmed the value of the lives of handicapped individuals.

It did so with an understanding of the advances in medicine, education, and other professions that have dramatically improved the lives of even severely handicapped people. This understanding is demonstrated not only in the text and legislative history of § 504 but also in the consistent pattern of other statutes enacted during the same period to improve services for handicapped people and to protect their civil rights. This history is totally inconsistent with the contention that Congress intended to exempt from § 504 discriminatory actions that devalue and endanger the lives of disabled children.

ARGUMENT

I. CONGRESS HAS RECOGNIZED THAT MODERN DEVELOPMENTS IN MEDICINE, EDUCATION, HABILITATION, AND OTHER SERVICES FOR NEWBORNS AND THEIR FAMILIES HAVE GREATLY ENHANCED THE LIVES OF HANDICAPPED PEOPLE.

The lives of people who are handicapped are protected by the Constitution and laws of the United States no less than those of nonhandicapped citizens. Congress, therefore, has chosen to prohibit invidious discrimination by recipients of federal funds—including the denial of life-saving medical treatment—solely on the basis of handicap. Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794. This statute is part of a larger pattern of legislation designed to assist handicapped people. *See City of Cleburne v. Cleburne Living Center*, 105 S. Ct. 3249, 3256 (1985). These federal statutes have provided opportunities for education and other assistance to handicapped people and have protected their rights.[1]

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[1] *See, e.g.*, Education of the Handicapped Act, 20 U.S.C. § 1400 *et seq.*; Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. § 6000 *et seq.* Congressional attempts to assist handicapped individuals date back at least to 1917. S. Rep. No. 318, 93d Cong., 1st Sess. 8, *reprinted in* 1973 U.S. Code Cong. & Ad. News

In enacting these statutes, Congress has recognized that advances in medicine, technology, special teaching techniques, and available professional services have dramatically improved the lives of handicapped citizens.[2] This

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2076, 2082. But the most significant enactments began in the 1970s, when dramatic advances in technology and professional techniques made community integration and participation possible for millions of handicapped persons who previously had been excluded from community life. *See generally* Thompson, Wilcox & York, *The Federal Program for the Severely Handicapped: Historical Perspective, Analysis and Overview*, in *Quality Education for the Severely Handicapped* 1 (B. Wilcox & R. York eds. 1980).

[2] *See, e.g.*, the statement of Senator Randolph, debating the attempt to override the veto of the Vocational Rehabilitation Act, about persons who are severely handicapped:

> We all know of the progress that has been made in the medical profession. We know of the improvements which have been made from the standpoint of prenatal and postnatal care, resulting in higher rates of survival among our multiple handicapped infants. The changing concept of the right to treatment, the advent of new drugs and new surgical techniques, permits lives previously lost to be saved. But patients are often left with physical or mental handicaps. Once we thought the lives of such people were a loss, that we could not return them to active levels of society where they would be productive citizens. Now, however, we know that that can be done. We know it has been done.

119 Cong. Rec. 10802 (1973). Senator Cranston, debating passage of the Rehabilitation Act, stated:

> I believe that our science and technology should not be withheld from those less fortunate persons, who because of their handicaps, cannot take full advantage of much of the technology we take for granted. . . . I think that simple justice requires that we give them the benefit of a more independent, self-sufficient, and remunerative existence.

119 Cong. Rec. 24568 (1973). In the Senate Report from the Committee on Labor recommending passage of the Education for All Handicapped Children Act, the Committee recognized that "[w]ith proper education services, many [handicapped children] would be able to become productive citizens, contributing to society instead of being forced to remain burdens." S. Rep. No. 168, 94th Cong., 1st Sess. 9 (1975), *reprinted in* 1975 U.S. Code Cong. & Ad. News

acknowledgement by Congress of the potential for improving the lives of handicapped individuals informs the appropriate interpretation of § 504. First, it demonstrates the implausibility of the argument that Congress intended to exclude this particular form of discrimination from the Secretary's enforcement responsibility under § 504. In addition, it highlights the inconsistency between the Second Circuit's requirement that the Secretary continue federal funding of discriminatory health care providers and the clear purpose of the statute that no federal funds should support discrimination against handicapped persons.

Discriminatory withholding of necessary and appropriate medical care and treatment from handicapped infants is primarily based on the assumption that these children's handicaps make their lives less valuable than those of babies who have no detectable disability, and even renders them "not worth living." [3] The professional experience of

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1425, 1433. The same report emphasizes that Congress placed the highest priority on educating the most severely handicapped children. *Id.* at 22, 1975 U.S. Code Cong. & Ad. News at 1446.

[3] The history of our society's treatment of handicapped people, which has been described by five members of this Court as "grotesque," *City of Cleburne v. Cleburne Living Center*, 105 S.Ct. 3249, 3262 (1985) (Stevens, J., concurring), 105 S.Ct. at 3266 (Marshall, J., concurring in part and dissenting in part), includes numerous suggestions that the lives of handicapped people should not be protected. *See, e.g.*, reference to proposed Iowa legislation in 1906 for "removal by the chloroform route," and the statement that "the two things are in line[:] . . . . the authority of the law to prevent defectives from being born, and the authority of the law to put them out of the world after they are born." Murdoch, *The Psychic Treatment of Mental Defectives*, 10 J. Psycho-Asthenics 224 (1906). *See also* Johnson, *Discussion on the Care of the Feebleminded and the Epileptic*, in *Proceedings of the National Conference of Charities & Corrections* 410-11 (1901), *quoted in* Herr, *Civil Rights, Uncivil Asylums, and the Retarded*, 43 U. Cinn. L. Rev. 679, 697-98 (1974) ("I do not think that to prevent the propagation of this class it is necessary to kill them off or resort to the knife; but, if it is necessary, it should be done."). *Cf.* Alexander, *Medical Science Under*

the members of *Amici* in a variety of disciplines belies this premise.[4]

Education is one of the areas in which the most dramatic developments have taken place in the last fifteen years. Before 1970, public schools routinely excluded mentally[5] and physically[6] handicapped children. This practice has been almost completely eradicated by enforcement of the Education of the Handicapped Act, 20 U.S.C. § 1400 *et seq.* This statutory right to an education has been accompanied by extraordinary advances in the instructional technology available for the education of even the most severely handicapped children.[7] It can now be stated categorically that all handicapped children can benefit from an education.[8]

Dictatorship, 241 New Eng. J. Med. 39, 40 (1949); Wolfensberger, *The Extermination of Handicapped People in World War II Germany*, 19 Mental Retardation 1 (1981). On occasion, the rhetoric in the modern debate on "quality of life" is uncomfortably reminiscent of its antecedents in American history. *See infra* note 30.

[4] *See* Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less than Human*, 23 Mental Retardation 148 (1985); Powell & Hecimovic, *Baby Doe and the Search for a Quality of Life*, 51 Exceptional Children 315 (1985).

[5] *See Pennsylvania Ass'n for Retarded Children v. Commonwealth of Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971), 343 F. Supp. 279 (E.D. Pa. 1972). *See also Board of Education v. State*, 47 Ohio App. 417, 191 N.E. 914 (1934); *Watson v. City of Cambridge*, 157 Mass. 561, 32 N.E. 864 (1893).

[6] *See, e.g., State ex rel. Beattie v. Board of Education*, 169 Wis. 231, 172 N.W. 153 (1919).

[7] *See, e.g.*, Stainback & Stainback, *A Review of the Research on the Educability of Profoundly Retarded Persons*, 18 Educ. & Training of the Mentally Retarded 90 (1983); Personnel Training Program for the Education of the Severely Handicapped, *Educational Technology for the Severely Handicapped: A Comprehensive Bibliography* (1975).

[8] *See, e.g.*, Education of the Handicapped Act, 20 U.S.C. § 1400 (congressional finding).

Widely accepted teacher-training textbooks in the area include *Systematic Instruction of the Moderately and Severely Handicapped*

For children with severe disabilities, this educational opportunity now provides self-help skills that enhance their independence and thus their ability to live in the community. Children, who in another era might have lacked the ability to feed and dress themselves and care for their own hygiene, can today expect to master these skills with the assistance of special education.[9] Parallel

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(M. Snell 2d ed. 1983); *Teaching the Severely Handicapped: Programs, Methods, and Materials* (N. Haring & L. Brown eds. 1976); W. Sailor & D. Guess, *Severely Handicapped Students: An Instructional Design* (1983); R. Gaylord-Ross & J. Holvoet, *Strategies for Educating Students with Severe Handicaps* (1985); G. Van Etten, C. Arkell & C. Van Etten, *The Severely and Profoundly Handicapped* (1980).

Amici respectfully suggest that this Court previously may have misperceived the degree of consensus among professionals on the question whether severely and profoundly mentally retarded adults and children can benefit from education and habilitation. *Cf. Youngberg v. Romeo*, 457 U.S. 307, 316-17 n.20 (1982). Methods for the education of severely and profoundly retarded individuals are universally accepted among professionals. Collectively, *Amici* encompass the broadest available spectrum of professional opinions about appropriate services for handicapped people, and can assure this Court that while disagreements exist about terminology, priorities, and particular techniques, there is no substantial professional opinion that holds severely and profoundly handicapped individuals to be incapable of benefiting from appropriately designed education and habilitation. *See* Ferleger, *Anti-Institutionalization and the Supreme Court*, 14 Rutgers L. J. 595, 628-32 (1983).

[9] *See, e.g.*, Banerdt & Bricker, *A Training Program for Selected Self-Feeding Skills for the Motorically Impaired*, 3 Am. Ass'n Educ. Severely/Profoundly Handicapped Rev. 222 (1978); Azrin & Armstrong, *The "Mini-meal"—A Method for Teaching Eating Skills to the Profoundly Retarded*, 11 Mental Retardation 9 (1973); Schlein, Ash, Kiernan & Wehman, *Developing Independent Cooking Skills in a Profoundly Retarded Woman*, 6 J. Ass'n for Severely Handicapped 23 (1981); Martin, Kehoe, et al., *Operant Conditioning in Dressing Behavior of Severely Retarded Girls*, 9 Mental Retardation 27 (1971); Horner & Keilitz, *Training Mentally Retarded Adolescents to Brush Their Teeth*, 8 J. Applied Behav. Analysis 301 (1975); Lancioni, *Teaching Independent Toileting to Profoundly Retarded Deaf-Blind Children*, 11 Behavior Therapy, 234 (1980); R. Foxx & N. Azrin, *Toilet Training the Retarded* (1973).

educational advances allow teachers to enhance a mentally disabled individual's ability to share social relationships [10] and to reduce "stereotypic" [11] and self-injurious behaviors.[12]

Handicapped children who previously would have been believed to be incapable of communication can now be taught and mechanically assisted in gaining this life skill.[13] Similarly, physical therapy and modern technological developments allow far greater mobility to many physically handicapped individuals.[14] New techniques in

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[10] *See, e.g.*, S. McClennen, R. Hoekstra & J. Bryan, *Social Skills for Severely Retarded Adults: An Inventory and Training Program* (1980); Day, Fox, et al., *The Social Competence Intervention Project: Developing Education Procedures for Teaching Social Interaction Skills to Handicapped Children*, 8 Behavioral Disorders 120 (1983); Peterson, Austin & Lang, *Use of Teacher Prompts to Increase Social Behavior: Generalization Effects with Severely and Profoundly Retarded Adolescents*, 84 Am. J. Mental Deficiency 82 (1979); Powell, Salzberg, et al., *Teaching Mentally Retarded Children to Play with their Siblings Using Parents as Trainers*, 6 Educ. & Treatment of Children 343 (1983).

[11] *See* American Association on Mental Deficiency, *Classification in Mental Retardation* 198 (H. Grossman ed. 1983).

[12] *See, e.g.*, Hollis, *Analysis of Rocking Behavior*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 1 (C.E. Meyers ed. 1978); Baumeister & Rollings, *Self-injurious Behavior*, in 8 *International Review of Research in Mental Retardation* 1 (N. Ellis ed. 1976); *Life-Threatening Behavior: Analysis and Intervention* (J. Hollis & C. E. Meyers eds. 1982).

[13] *See, e.g.*, McDonald, *Design and Application of Communication Boards, in Non-vocal Communication Techniques and Aids for the Severely Physically Handicapped* 105 (G. Vanderheiden & K. Grilley eds. 1975); Kuntz, Carrier & Hollis, *A Nonvocal System for Teaching Retarded Children to Read and Write*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 145 (C.E. Meyers ed. 1978); Bricker, *Early Communication: Development and Training*, in *Systematic Instruction of the Moderately and Severely Handicapped* 269 (M. Snell 2d. ed. 1983).

[14] *See, e.g.*, Campbell, *Basic Considerations in Programming for Students with Movement Difficulties*, in *Systematic Instruction of*

vocational training and the availability of sheltered and competitive employment opportunities have increased the number of handicapped people who can be gainfully employed.[15]

The combination of all these developments, together with the increased accessibility of generic services which has accompanied the implementation of § 504, has made it possible for virtually all of the nation's handicapped citizens to live in their own communities.[16] This is as

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the Moderately and Severely Handicapped 168 (M. Snell 2d ed. 1983).

[15] *See* G.T. Bellamy, D. Horner & R. Inman, *Vocational Habilitation of Severely Retarded Adults: A Direct Service Technology* (1979); Bellamy, Sowers & Bourbeau, *Work and Work-Related Services: Postschool Options*, in *Systematic Instruction of the Moderately and Severely Handicapped* 490 (M. Snell 2d ed. 1983); Rusch, *Competitive Vocational Training*, in *Systematic Instruction of the Moderately and Severely Handicapped* 503 (M. Snell 2d ed. 1983).

[16] Of the many scientific studies of this issue, perhaps the most thorough and persuasive is the one that grew out of the deinstitutionalization and imminent closure of Pennhurst. *Cf. Youngberg v. Romeo*, 457 U.S. 307 (1982); *Pennhurst State School & Hospital v. Halderman*, 465 U.S. 89 (1984). J. Conroy & V. Bradley, *Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (Temple Univ. & Human Services Research Inst. Mar. 1985) (finding that all Pennhurst residents—regardless of level of mental retardation—could be served successfuly in the community). *See also* K. Casey, J. McGee, J. Stark & F. Menolascino, *A Community-Based System for the Mentally Retarded: The ENCOR Experience* (1985) (describing one major metropolitan area that serves virtually all its mentally retarded citizens—regardless of level of disability—in the community); *Deinstitutionalization and Community Adjustment of Mentally Retarded People* (R. Bruininks, C.E. Meyers, B. Sigford & K.C. Lakin eds. 1981); President's Committee on Mental Retardation, *Mental Retardation: The Leading Edge—Service Programs That Work* 33-42 (11th Annual Report to the President 1979). *Dicta* from previous cases have suggested that some members of this Court may be in doubt as to whether there is a substantial sub-class of mentally retarded people who are so severely retarded that they are incapable of living and receiving services in the community. The professional experience of those

true for children as it is for adults.[17]

Of particular significance for the case at bar are the medical advances that have made it possible to save the lives and lengthen the lifespan of handicapped people[18] and, in many cases, even to reduce the level of their disability. These advances include the very treatment modalities that have been denied to handicapped children in the notorious "Baby Doe" cases. Corrective surgery for the blockage that prevents some infants with Down syndrome from digesting food has become a routine procedure. Shunting of excess fluid from babies born with hydrocephalus can greatly reduce the pressure on their brains and thus eliminate or minimize the possibility of resulting mental retardation. Surgically enclosing the sac of infants born with spina bifida can prevent infection and its attendant risk of mental disability. Orthopedic surgery can increase the mobility of many children with spina bifida. Developments in modern cardiac surgery have made it possible to correct many of the heart defects that sometimes accompany Down syndrome. *Cf. Guardianship of Phillip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983).[19]

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most directly involved in serving these individuals indicates that no such sub-class exists.

[17] The ability of children to live in the community is enhanced by the development of support services for their families, and by alternative community living arrangements for children whose families are unable to keep them at home even with additional support. *See, e.g.*, Upshur, *An Evaluation of Home-Based Respite Care*, 20 Mental Retardation 58 (1982); Timm & Rule, *RIP: A Cost-Effective Parent-Implemented Program for Young Handicapped Children*, 7 Early Child Dev. & Care 147 (1981); W. Sailor & D. Guess, *Severely Handicapped Students: An Instructional Design* 319-39 (1983).

[18] *See, e.g.*, D. MacMillan, *Mental Retardation in School and Society* 343 (2d ed. 1982).

[19] Phillip Becker, a teenager with Down syndrome, was originally denied corrective surgery for a heart defect. Following litigation,

Taken together, these developments have greatly improved the true "quality" of the lives of handicapped people. Congress's awareness of these advances has accompanied and stimulated its efforts to protect the civil rights of these citizens. This fact refutes the contention that Congress somehow intended to exclude the discriminatory withholding of life-saving medical care and treatment from the scope of its prohibition on discrimination against handicapped people. This Court should not interpret § 504 in a manner inconsistent with the policy that Congress clearly sought to implement.

II. PREDICTIONS ABOUT THE FUTURE "QUALITY OF LIFE" OF INDIVIDUAL NEWBORNS ARE NOT UNIQUELY MEDICAL JUDGMENTS IMMUNE FROM CIVIL RIGHTS LAWS.

Debates about the appropriate care and treatment of infants born with evident handicaps almost invariably turn to discussion of the prospect for the child's "quality of life." It is no surprise, therefore, that the professional literature makes it abundantly clear that the child's "quality of life" is a major factor in the decision of some health care providers to deny medical care to handicapped newborns. To understand the practice of withholding such treatment, it is necessary to review this literature about "quality of life" and the role it plays in this discriminatory practice.

Speculation about a child's future "quality of life" typically involves an insidious combination of both dubious predictions about the course of that life and subjective value judgments about what kinds of lives are worth (or not worth) living. Neither of these components is

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the surgery was performed successfully. Herr, *The Phillip Becker Case Resolved: A Chance for Habilitation*, 22 Mental Retardation 30, 31 (1984).

uniquely within the professional expertise of physicians.[20] Thus neither is the kind of medical judgment that is beyond appropriate review for possible discrimination under the nation's civil rights laws.[21]

As the literature in the journals of health care professions demonstrates, there are significant errors and bias in the factual assumptions made by those health care providers who illegally withhold needed medical treatment.[22] For example, a substantial number of doctors who deny appropriate care and treatment to handicapped babies significantly underestimate the children's actual chances for survival if treatment were provided.[23] Physi-

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[20] Indeed, the American Academy of Pediatrics and the other signatory organizations to the *Joint Policy Statement on Principles of Treatment of Disabled Infants* have agreed that the common components of predictions of "quality of life" are impermissible considerations in the decision about medical care and treatment. "Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care." *See* Appendix to this brief.

[21] The scope of matters believed to be within the exclusive province of physicians has varied throughout our history. *See generally* P. Starr, *The Social Transformation of American Medicine* (1982).

[22] The membership of *Amici* includes many health care providers, including numerous physicians who specialize in treating disabled individuals. It is certainly not the contention of *amici* that most health care providers or most physicians discriminate against handicapped children. But the fact that some who do withhold care and treatment on a discriminatory basis are medical professionals does not render their actions any less discriminatory. This is equally true for those health care providers who discriminate because they lack accurate information about modern prospects for the lives of handicapped individuals and for those whose actions may be motivated by a belief that the lives of handicapped people are less valuable than other lives.

[23] *See* Clyman, Sniderman, Ballard & Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counseling Process*, 63 Pediatrics 719 (1979); Goldenberg, Nelson, Dyer & Wayne, *The Variability of Viability: The Effect of Phy-*

cians without practical experience with handicapped individuals are also likely to grossly underestimate what a handicapped child will be able to learn and accomplish.[24] In addition, a remarkable number lack up-to-date knowledge about the availability of community services for people with mental retardation.[25] Since pediatricians and other physicians receive very little training in the area of mental and physical disability in the course of their medical education,[26] these problems are exacerbated if the physician fails to seek consultation and assistance from professionals with experience and expertise in the relevant area of disability.[27]

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sicians' Perceptions of Viability on the Survival of Very Low-Birth Weight Infants, 143 Am. J. Obstet. & Gynecol. 678 (1982).

[24] A recent study found that general pediatric practitioners were significantly more pessimistic about the developmental potential of mentally retarded people than professionals with more direct experience in the field. Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983). Another study revealed that only a small percentage of pediatric surgeons reported that their estimation of a child's potential for integration into his family was based on "acquaintance with the mental retardation literature." Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 588, 595 (1977). *See also infra* text accompanying notes 36-41; Walker, Feldman, Vohr & Oh, *Cost Benefit Analysis of Neo-Natal Intensive Care for Infants Weighing Less than 1000 Grams at Birth*, 74 Pediatrics 23 (1984).

[25] Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Mentally Retarded*, 13 Mental Retardation 10 (1975). These services directly and significantly affect handicapped children throughout their lives and therefore would be a crucial component if the "quality of life" inquiry were legitimate.

[26] American Academy of Pediatrics Task Force on Pediatric Education, *The Future of Pediatric Education* (1978).

[27] "Because of the explosive increase in factual and technical knowledge, few individual physicians are now able to diagnose an infant's condition and assess accurately the child's prognosis without extensive input from other specialists. If there is one major problem in decision making for handicapped newborns, it is the

Given these substantial limitations on the information possessed by a substantial number of health care providers, it is not surprising that their decisions and the information they convey to parents are, in some cases, based on the same false stereotypes about handicapped people that remain prevalent in the population at large.[28] *See City of Cleburne v. Cleburne Living Center*, 105 S. Ct. 3249, 3267 (1985) (Marshall, J., concurring in part and dissenting in part). Indeed, parents of handicapped children still consistently report that health care providers misinformed them about the nature of their child's handicapping condition and the prospects for the child's development, education, and future.[29]

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matter of provision of factual information." Johnson & Thompson, *The "Baby Doe" Rule: Is It All Bad?*, 73 Pediatrics 729 (1984).

[28] It was the effects of such prejudice and ignorance, of course, that § 504 was designed to correct.

[29] *See* R. Darling, *Families Against Society*, 128-45 (1979); Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, 11 Hastings Center Rep. 17 (1981); H.R. Turnbull & A. Turnbull, *Parents Speak Out: Then and Now* (2d ed. 1985). *See also Amici Curiae* brief of Association for Retarded Citizens, *et al.*

In their briefs in opposition to the writ of certiorari, Respondents attempted to persuade this Court that § 504 is inapplicable to the discriminatory denial of medical care and treatment to handicapped infants because health care providers merely make recommendations to a child's parents, who, in turn, make the final decision. This argument ignores the crucial weight that parents typically accord to the recommendations of their doctor and the unique vulnerability of parents upon being told that their newborn baby is "deformed" or "defective." *See, e.g.*, Darling, *Parents, Physicians and Spina Bifida: A Study of Values in Conflict*, 7 Hastings Center Rep. 10 (1977). The transparency of the argument that discriminatory health care providers are merely the agents of discriminatory parents is illustrated by the suggestion of one physician that parents should not be encouraged to nurture their newborn handicapped baby lest a bond be established that might cause the parents to make a "selfish" decision to order the provision of life-saving treatment, Cassell, *Nurturing a Defective Newborn: Commentary*, 8 Hastings Center Rep. 13, 14 (1978), and the admonition by a leading pediatrician that physicians who believe it to be desirable to

The other principal component of predictions about a baby's "quality of life" is a subjective judgment by the discriminatory health care provider about the value of the child's life. Discriminatory health care providers may evaluate the worth of a handicapped child's life in light of prejudices toward disabled people that do not differ in any relevant way from that of other prejudiced individuals in society.[30]

But even when a discriminatory health care provider does not openly reveal archaic stereotypes or overt prejudice, other factors reported in the professional litera-

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withhold treatment from a child should be patient since "[f]irm rooting of a parental death wish for a defective child usually takes days, at least; and it is never free of ambivalence." Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with "Medical Vietnam,"* 67 Pediatrics 315, 317 (1981).

[30] *See, e.g.*, Singer, *Sanctity of Life or Quality of Life?*, 72 Pediatrics 128, 129 (1983) ("If we compare a severely defective human infant with a nonhuman animal, a dog or a pig, for example, we will often find the nonhuman to have superior capacities, both actual and potential, for . . . anything . . . that can plausibly be considered morally significant."); Bard & Fletcher, *The Right to Die*, The Atlantic Monthly 59, 64 (Apr. 1968) ("[There is] no reason to feel guilty about putting a Down's syndrome baby away, whether it's 'put away' in the sense of hidden in a sanitarium or in a more responsible lethal sense. . . . True guilt arises only from an offense against a person, and a Down's is not a person. . . . Guilt over a decision to end an idiocy would be a false guilt, and probably unconsciously a form of psychic masochism.").

As in other areas of indivious discrimination, terminology can be a means of affirming or devaluing the lives of handicapped people. Those who would not acknowledge the full humanity of handicapped babies seem particularly fond of the term "defective," either as a noun or adjective, which may connote a poorly manufactured product that can be discarded. Far worse are references to handicapped children as "vegetables." For eloquent criticism of this usage, see Hentoff, *The Awful Privacy of Baby Doe*, The Atlantic Monthly 54, 57 (Jan. 1985). *See generally*, G. Will, *"The Killing Will Not Stop,"* The Washington Post, Apr. 22, 1982, at A29.

ture indicate illegal discrimination against handicapped children. Numerous recent studies and surveys indicate that some physicians weigh social and economic factors in deciding whether to recommend that routine medical care be withheld from a handicapped infant.[31] The contemporary literature contains several examples of proposed guidelines for the withholding of care that include such factors.[32] A particularly offensive example of the implementation of these suggestions by a recipient of federal funds is the pseudo-experimental triage of spina bifida babies described in the *Amicus* brief of Carlton Johnson.[33] Consideration of these non-medical factors means that life-or-death treatment decisions may be made on the basis of the wealth or education of a child's parents or the attributes of the community in which he is born.[34]

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[31] *See, e.g.*, Affleck, *Physicians' Attitudes Toward Discretionary Medical Treatment of Down's Syndrome Infants*, 18 Mental Retardation 79 (1980); McDonald, Carson, Palmer & Slay, *Physicians' Diagnostic Information to Parents of Handicapped Neonates*, 20 Mental Retardation 12 (1982); Todres, Krane, Howell & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197 (1977); Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 Pediatrics 17, 20 (1979).

[32] *See, e.g.*, Shurtleff, Hayden, Lowser, & Kronmal, *Myelodysplasia: Decision for Death or Disability*, 291 New Eng. J. Med. 1005 (1974); Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 Pediatrics 17 (1979). One author even reduced these factors to a pseudo-algebraic scheme that purports to provide a mathematical formula for weighing the child's "natural endowment," and "contributions" anticipated from both his family and his community. Shaw, *Defining the Quality of Life: A Formula Without Numbers*, 7 Hastings Center Rep. 11 (1977).

[33] *See* Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983); Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 Issues in Law & Medicine 15 (1985); Krauthammer, *What to Do About 'Baby Doe,'* The New Republic 16 (Sept. 2, 1985). Cf. J. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (1981).

[34] Without more, making treatment decisions on the basis of family wealth, education, or even race would not violate § 504,

Two state supreme courts have wisely concluded that speculating about the future "quality" of a person's life is a perilous endeavor. The Supreme Judicial Court of Massachusetts, in a landmark case, firmly rejected the equation of the supposed "quality" of a disabled man's life with assigning a reduced value to that life. That court declared that any presumed diminution of a mentally handicapped man's ability "to appreciate or experience life" attributed to his mental retardation could have no proper role in deciding whether he was to receive medical treatment. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 738, 754, 370 N.E.2d 417, 432 (1977). The Supreme Court of New Jersey recently issued a similar declaration:

> [W]e expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others. We do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's "quality of life" or value to society seems negligible. . . . More wide-ranging powers to make decisions about other people's lives, in our view, would create *an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps.*

In re Conroy, 98 N.J. 321, ——, 486 A.2d 1209, 1232-33 (1985) (emphasis added). The devaluation of a person's life because of his handicap by withholding care and treatment that would be provided to a non-disabled individual is also a practice wholly inconsistent with the spirit and letter of § 504.

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although other civil rights protections could be applied. But the fact that these factors are considered *only* for handicapped infants clearly indicates the kind of discrimination that § 504 was intended to address.

Amici do not mean to suggest that all possible forms of medical treatment must be provided to every handicapped newborn infant. For example, the *Joint Statement of Principles* makes clear that treatment need not be provided if it will merely prolong the process of a person's inevitable death. *See* Appendix. But that same *Joint Statement* also stipulates that it is *never* acceptable to withhold appropriate medical care and treatment solely on the basis of an individual's handicap. This is precisely the effect of acknowledging the applicability of § 504, and for this reason, the signatories of the *Joint Statement of Principles* recognized the importance of § 504 in protecting the rights of these children.[35]

Decisions to withhold medical treatment on the basis of a child's handicap, particularly when grounded in speculation about the quality of that child's future life, are not uniquely medical judgments. This is because such decisions do not rely on knowledge uniquely, or even primarily, within the possession of the medical profession. Therefore, this Court's admonition that deference is due to the professional judgments of disability professionals does not support Respondents' position in this case. *Cf. Youngberg v. Romeo*, 457 U.S. 307, 322 (1982).

A more relevant maxim is this Court's observation that in the field of disability, "courts should pay particular deference to reasonable legislative judgments." *Jones v. United States*, 463 U.S. 354, 380 n.13 (1983). Congress fully informed itself about the nature of disability and the lives of handicapped citizens before enacting § 504 and other contemporaneous legislation on behalf of handicapped people. This Court should not allow Congress's

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[35] "The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimination against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act." *See* Appendix to this brief.

consistent, considered judgment about the value of the lives of these individuals to be overturned by the subjective, speculative opinions of others about whether those lives are "worth" living.

Deferring to Congress's judgment on this point is made all the more unobjectionable by the fact that the disabilities most frequently at issue in the "Baby Doe" cases are not as catastrophic as the general public[36] (and apparently some health care professionals) believe. Children born with Down syndrome are mentally retarded (typically at the mild or moderate level), but all can benefit from academic and vocational education and can lead full and productive lives.[37] Infants born with spina bifida will not necessarily be mentally retarded[38] and a large majority of them can lead independent lives.[39] The pres-

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[36] The public's perception of these cases, already colored by widespread misunderstanding and fear concerning handicaps, can be further affected by journalistic accounts that reflect and exploit those fears. *See* Baer, *The Half-Told Story of Baby Jane Doe*, Colum. Journalism Rev. 35 (Nov./Dec. 1984).

[37] *See generally* N. Hunt, *The World of Nigel Hunt: The Diary of a Mongoloid Youth* (1967); G. Will, *"The Killing Will Not Stop,"* The Washington Post, April 22, 1982, at A29; *Down Sydrome: Advances in Biomedicine and the Behavioral Sciences* (S. Pueschel & J. Rynders eds. 1982). Recently, Senator John Chafee hired a teenager with Down syndrome as a congressional page. *Capitol Hill Page Joe Connors Displays a Pioneering Spirit*, The Albuquerque Tribune, July 26, 1985, at B-3 (Scripps Howard News Service).

[38] Children born with myelomeningocele who receive the medically indicated shunt (or who did not require a shunt) and who do not get infections have average IQs. McLone, Czyzewski, Raimondi & Sommers, *Central Nervous System Infections as a Limiting Factor in the Intelligence of Children with Myelomeningocele*, 70 Pediatrics 338 (1982).

[39] McLone, *Results of Treatment of Children Born with a Myelomeningocele*, 30 Clinical Neurosurgery 407 (1983). An example is an individual with spina bifida who recently received an honors degree in sociology. Davis, *Right to Life of Handicapped (Correspondence)*, 9 J. Med. Ethics 181 (1983).

ence before this Court of a number of self-advocacy groups as *Amici Curiae* in this case [40] is a further indication of the correctness of the judgment of Congress that the lives of handicapped people are valuable lives that should be protected by law.[41]

III. FEDERAL CIVIL RIGHTS ENFORCEMENT IS AN APPROPRIATE RESPONSE TO THE PROBLEM OF DISCRIMINATION AGAINST HANDICAPPED INFANTS.

This case presents the narrow question whether § 504 reaches discriminatory denial of nutrition and medical care and treatment to handicapped newborn babies. Therefore, the details of the Secretary's previous regulations are not at issue. This Court need not, and should not, consider the appropriateness of any particular regulations or techniques of enforcement.[42]

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[40] *See also* P. Williams & B. Shoultz, *We Can Speak for Ourselves: Self Advocacy By Mentally Handicapped People* (1984); Stanovich & Stanovich, *Speaking for Themselves: A Bibliography of Writings by Mentally Handicapped Individuals,* 17 Mental Retardation 83 (1979).

[41] In popular discussion, the birth of a handicapped child is often spoken of as a "tragedy." It is indeed tragic when a child is born with a disabling condition that could have been prevented. (Many handicapping conditions can now be prevented by nutritional, dietary, and other kinds of interventions. *Amici* have been active in seeking implementation of measures to prevent this unnecessary incidence of handicaps.) But it is often said that the birth itself is a "tragedy." This view suggests a conclusion that the lives of handicapped people are worthless. Congress clearly did not view the lives of people with handicaps as valueless. Instead, it attempted, through § 504, to prevent unwarranted discrimination from adding to the burdens that handicapped people already bear. A handicapped child is, first and foremost, a child; its handicap is not the entirety of its being any more than its race or gender.

[42] If the decision of the Court of Appeals is reversed and the Secretary is permitted to promulgate regulations, *Amici* will then take the opportunity to make their views known on the details of the proposed regulations.

Amici recognize that enforcement of civil rights laws sometimes can be inconvenient and even disruptive for health care providers. For this reason, within the range of effective enforcement mechanisms, *Amici* believe that the least disruptive means should always be preferred. But the fact that enforcement of § 504 might create some inconvenience for the recipients of federal funds does not mean that Congress intended for this kind of discriminatory decision-making (or even medical care as a whole) to be exempt from the statute's requirements. Congress has long recognized that the enforcement of civil rights laws carries with it a necessary, albeit regrettable, measure of inconvenience for a variety of individuals and institutions in our society. Nevertheless, it has consistently concluded that the rights at issue were of sufficient magnitude to outweigh the burden placed on those who might be accused of discriminatory actions.[43] It certainly cannot be maintained that the stakes for a baby who may be unlawfully deprived of nutrition or life-saving medical care and treatment are smaller than in cases that involve educational placement or employment discrimination.

Equally unpersuasive is the suggestion that the enactment of the Child Abuse Amendments of 1984, Pub.L. No. 98-457, 98 Stat. 1749 *et seq.*, somehow strips § 504 of its applicability to this kind of discrimination. It should first be noted that Congress explicitly denied any such intention.[44] Further, the existence of federal en-

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[43] *See, e.g.*, 121 Cong. Rec. 25540 (1975) (remarks of Rep. Miller on the administrative burdens of the Education of the Handicapped Act).

[44] "No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973." Child Abuse Amendments of 1984 § 127(a), Pub. L. No. 98-457, § 127(a), 98 Stat. 1749, 1754. *See Watt v. Alaska*, 451 U.S. 259, 267 (1981) (legislative intention to repeal a statute must be clear and manifest); *Morton v. Mancari*, 417 U.S. 535, 551 (1974) ("The courts are not at liberty to pick

couragement for state remedies does not obviate the need for federal enforcement in those cases where states fail to protect the lives of handicapped children. This is not the only area of civil rights law in which state provisions parallel those in federal statutes. *Amici* do not dispute that state enforcement in individual cases of discrimination is often preferable to federal enforcement. But, as in other areas of civil rights enforcement, experience suggests that states will not be uniformly diligent in carrying out their responsibilities. Federal enforcement capability is therefore appropriate and necessary to guarantee that handicapped children are not denied protection of their right to nutrition or medical care merely because of their state of residence.

The argument that the Child Abuse Amendments somehow supplant § 504 also requires attribution to Congress of inconsistent and anomalous purposes and methods. Section 504 declares that federal funds will not be used in discriminatory ways. The Child Abuse Amendments require the withdrawal of federal funds from state child welfare agencies that do not protect handicapped children from discriminatory denial of treatment. But if the latter law were interpreted to eliminate enforcement of the former statute, the Secretary would be required to *deny* funds to the welfare agency but would be required to *continue* funding the recipient who actually engaged in the discriminatory conduct. It is well settled that statutes should not be interpreted in a way that would produce absurd results. *United States v. Turkette*, 452 U.S. 576, 580 (1981).

Amici believe that § 504 is a tool that is as essential for the protection of handicapped infants as it is for other handicapped people. Its protections are literally a matter of life and death for some of the most vulnerable of our nation's citizens.

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and choose among congressional enactments, and when two statutes are capable of co-existence, it is the duty of the courts, absent a clearly expressed congressional intention to the contrary, to regard each as effective.").

CONCLUSION

For the reasons set forth above, *Amici* urge this Court to reverse the judgment of the Second Circuit.

Respectfully submitted,

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APPENDIX

The following Joint Statement is reprinted from 73 Pediatrics 559 (1984). *See also* 49 Fed. Reg. 1622, 1652 (Jan. 12, 1984).

JOINT POLICY STATEMENT

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Discrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible.

Throughout their lives, all disabled individuals have the same rights as other citizens, including access to such major societal activities as health care, education, and employment.

These rights for all disabled persons must be recognized at birth.

NEED FOR INFORMATION

There is a need for professional education and dissemination of updated information which will improve decision-making about disabled individuals, especially newborns. To this end, it is imperative to educate all persons involved in the decision-making process. Parents should be given information on available resources to assist in the care of their disabled infant. Society should be informed about the value and worth of disabled persons. Professional organizations, advocacy groups, the government, and individual care givers should educate and inform the general public on the care, need, value, and worth of disabled infants.

MEDICAL CARE

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not

available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration [sic] such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

GOVERNMENT AND COMMUNITY SUPPORT

Once a decision to treat an infant has been made, government and private agencies must be prepared to allocate adequate resources for appropriate services as needed to child and family for as long as needed. Services should be individualized, community-based, and coordinated.

The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimina-

tion against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act. States also have legitimate roles in protecting the rights of their citizens and an obligation to enforce all applicable state laws.

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No. 84-1529

IN THE
SUPREME COURT OF THE UNITED STATES

OCTOBER TERM, 1985

MARGARET M. HECKLER, Secretary of
Health and Human Services, Petitioner

v.

AMERICAN HOSPITAL ASSOCIATION, et al.,
Respondents.

On Writ of Certiorari to the
United States Court of Appeals for
the Second Circuit

DISABILITY RIGHTS EDUCATION & DEFENSE
FUND, INC.
WOMEN'S LECAL DEFENSE FUND

BRIEF OF AMICI CURIAE

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IN THE
SUPREME COURT OF THE UNITED STATES

OCTOBER TERM, L985

No. 84-1529

MARGARET M. HECKLER,
Secretary of Health
and Human Services, Petitioner

v.

AMERICAN HOSPITAL ASSOCIATION, et al.

On Writ of Certiorari to the
United States Court of Appeals for
the Second Circuit

DISABILITY RIGHTS EDUCATION & DEFENSE
FUND, INC.
WOMEN'S LEGAL DEFENSE FUND

BRIEF OF AMICI CURIAE

INTEREST OF AMICI CURIAE

The Disability Rights Education & Defense Fund, Inc. (DREDF) is a not for profit benefit corporation founded in 1979 by disabled adults and parents of disabled children to address national long-term disability rights reform from the perspective that all disabled people have the right to lead full and integrated lives, with the freedomm and dignity guaranteed to all members of our society. Many of the disabled people and parents of disabled children whom DREDF serves have been given unduly pessimistic and limiting opinions from medical personnel which have turned out to be no more than unfounded speculation. Parents have been informed that their newborns would never be able to do things which they

can now do. Disabled adults have been told that they are not capable of performing jobs which they now hold. Employers often rely on the opinions of doctors to document the inability to hold the job.

Disabled people and parents of disabled children have an interest in assuring that stereotypes and speculation are not used as the basis for decision-making, whether in employment, education, or health care. Disabled people and parents look to Section 504 to ensure that decisions affecting their lives are free from discriminatory bias. The integrity of Section 504 is challenged by this litigation. Amicus seeks to preserve the intended purpose and scope of Section 504.

The Women's Legal Defense Fund, Inc., founded in 1971, is a non-profit membership organization of over1,200 members, with the purpose of challenging sex discrimination through litigation, public education, counseling, and other forms of advocacy. It has long been concerned with ensuring that civil rights protections be interpreted broadly to protect the interests of those whom they were meant to serve. The Women's Legal Defense Fund has thus filed numerous amicus briefs in this and other courts in cases involving the interpretation of civil rights statutes. In particular the Women's Legal Defense Fund is concerned with the implications of this decision for disabled women and parents of disabled

children as well a for its impact on the development of civil rights law.

SUMMARY OF THE ARGUMENT

The American Hospital Association asks this Court to decide, as a matter of law, that the decision to withhold nutrition or treatment to a child with disabilities is never discrimination within the meaning of Section 504. Heckler v. American Hospital Association, No. 84-1529, Brief of the Respondents American Hospital Association, et al., In Opposition [to Petition for Certiorari] (May 25, 1985). The history of discrimination against people with disabilities and the similar histories of discrimination

against racial minorities and against women, belie this proposition.[1]

This brief will demonstrate that people with disabilities are subjected to the same kinds of discrimination that have been used against other minorities and against women. It will draw into question the assumptions about people with disabilities which give rise to discriminatory actions.

There is no longer any question that racial and ethnic minorities are entitled to the application of the same medical standards as are applied to white patients. If a black child and a white child present the same treatable

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1. This brief does not address the particulars of the subject regulations, but rather, the more general question of whether Section 504 applies to newborns with disabilities.

condition, we expect the health care facility to provide the same treatment for one as is provided for the other. Race is no longer deemed a basis upon which to provide different care. The same is true if male and female newborns present the same treatable conditions. Similarly, a disabled child should not be subjected to a different standard of medical care solely because of disability. Medical judgments are not immune from discriminatory bias and should not be shielded from judicial scrutiny.

Stereotypes which are today considered unfounded or even deplorable, have at other times operated to exclude and segregate minorities, women, and disabled people. In health care, as well as in

education, employment, and all facets of life, different standards have been applied to racial minorities, women, and to people with disabilities, because of society's perception of them as "subhuman," as "sick," or as "inferior." Increased social awareness of the irrational bases for the stigma associated with being black, or Hispanic, female, or disabled, and the resulting barriers to their being accepted as equals, have led to legislative and judicial decisions that prohibit such discrimination.

It is still difficult for many to understand that the different treatment of people with disabilities is based on prejudiced and irrational bases. Many still assume that disabled children are excluded from school or segregated from

their nondisabled peers, because they cannot learn or because they need special protection. The absence of disabled coworkers is often considered confirmation of the obvious "fact" that disabled people can't work. Similarly, people assume that different medical standards should apply to patients with disabilities because of stereotyped assumptions about their abilities or their quality of life.

Yet the Congress recognized the parallel histories of people with disabilities and racial and ethnic minorities and women. As a result, the Congress based Section 504 of the Rehabilitation Act of 1973 on Title VI of the Civil Rights Act of 1964, and on Title IX of the Education Amendments of 1972. Section 504 evidences Congress'

recognition that, as with racial minorities and women, legislation was necessary to ameliorate widespread, institutionalized discrimination. Further, as with racial minorities and women, Section 504's antidiscrimination language acknowledges that many of the problems faced by people with disabilities are not an inevitable consequence of physical or mental traits themselves, but rather of the false perceptions and prejudices others hold about those traits.

Given the Congress' intention that Section 504 be applied consistently with Title VI, it follows that the protections of Section 504 apply from the moment of birth. It also follows that the United States Department of Health and Human Services did have

authority to issue regulations specifically addressing the application of Section 504 to disabled newborns in a hospital which received federal financial assistance.

Argument

I. In the Context of Education and Employment, Stereotypes About Racial Minorities, Women and People With Disabilities Have Resulted in Similar Manifestations of Discrimination and Have Been the Subject of Similar Legislative and Judicial Decisions.

Distorted perceptions and false beliefs as to the uneducability and intellectual inferiority of disabled people have resulted in educational discrimination and segregation. Similarly, biased perceptions about people with disabilities have prevented vast numbers of otherwise qualified employees from ever getting jobs. U.S.

Civil Rights Commission, Accommodating the Spectrum of Individual Abilities, 29-32 (1984) (hereafter, Spectrum). Those perceptions echo the beliefs held for generations concerning the uneducability and intellectual inferiority of racial minorities and women and have also resulted in their denial of educational and employment opportunities.

The theories which were used to discriminate against blacks and against the disabled, in employment and education, are notably similar. In 1912, for example, one author reflected popular sentiment when he described people with retarded intellectual abilities as :

> causative factor in the production of crime, prostitution, pauperism,

> illegitimacy, intemperance, and other complex social diseases ... The feebleminded are a parasitic, predatory class, never capable of self-support or of managing their own public charges in some form. They cause unutterable sorrow at home and are a menace and danger to the community. Fernald, The Burden of Feeblemindedness, M.J. of Psychoasthenics, 90 (1912).

Corresponding perceptions of blacks had been used to buttress slavery:

> 'look,' commanded a Georgia physician, 'at his [the black's] small brain, his deficient intellection, his small lungs and defective atmospherization, his increased liver, his black blood and sluggish circulation, his obtunded nervous sensibility, his enlarged glandular system, all pointing to a physical character, animal in its inclinations and wanting in those attributes of intelligence which elevate the white man and places him far above the brute.' K. Kiple, Another Dimension To The Black Diaspara: Diet, Disease, And Racism 181-182 (1981) (hereafter, Kiple).

Similarly, false perceptions and prejudices concerning women's innate educational inferiorities were based in the nineteenth-century on physicians' beliefs that education was unsuitable for women:

> A young woman, however, who consumed her vital force in intellectual activities was necessarily diverting these energies from the achievement of true womanhood. She would become weak and nervous, perhaps sterile, or more commonly, and in a sense more dangerously for society, capable of bearing only sickly and neurotic children -- children able to produce only feebler and more degenerate versions of themselves. The brain and ovary could not develop at the same time. Society, mid-century physicians warned, must protect the higher good of racial health by avoiding situations in which adolescent girls taxed their intellectual faculties in academic competition. "Why," as one physician pointedly asked, "spoil a good mother by making an ordinary grammarian?" Rosenberg, The Female Animal: Medical and

> Biological Views of Woman and Her Role in Nineteenth-Century America in Women And Health In America --Historical Readings 15 (J. Leavitt, ed. 1984) (citations omitted).

Prejudice as to the educational limitations of women relegated them to a separate and discriminatory system of education:

> There was a time when the most common idea was that [a woman] was better off with little education. Later the doctrine developed that she should not be denied education, but that her education should be of a special type, fitting her for her 'place' in society and usually directed more on training her hands than her brains.

Myrdal, G., An American Dilemma,, 1944, in Roots Of Bitterness: Documents Of The Social History Of American Women 144 (N. Cott, ed. 1972).

Discriminatory educational theories had destructive effects on

black children which exceeded the undermining of educational motivation, affecting the entire emotional, moral and spiritual development of the child. These effects were well documented, and were acknowledged by this Court in Brown v. Board of Education, 347 U.S. 483, 494 (1954).

The distorted perceptions of the ineducability and intellectual inferiority of black children posed additional barriers to their education.

> [There is a vicious cycle of actions and attitudes underlying the difficulties which have led so many educators to conclude that many of these children are uneducable and "hopeless." In this cycle cultural discrepancies and alienation tend to orient the children toward low educational commitment and accomplishment. This orientation appears to the school as evidence that a low level of expectation concerning learning by these children is justified. Hearings before House

> Subcommittee on Integration in Federally Assisted Education on H.R. 6938, 87th Cong., 2nd Sess. (March 1962), 105 (Statement of John Niemeyer, Pres. of Bank St. College of Education, N.Y., N.Y.).[2]

This "vicious cycle" syndrome is as painfully applicable for the education of disabled students as it is

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2 Also see, Gliedman and Roth, The Unexpected Minority, (1980), in which the authors discuss the close nexus between segregation and the classification of racial and ethnic minorities as mentally retarded.

> In New York State in the 1960's a black child was twice as likely to be classified as mentally retarded if he attended a racially mixed school than if he attended a school that was mainly black. In other words, when black children were not already receiving a segregated education by virtue of segregated residential patterns, the school frequently perpetuated segregation within the programmatic framework of integration by overlabeling black children as "mentally retarded." Id. at 179.

for racial minorities. First, the stigma of being disabled, which attaches in the primary grades, results in lifelong labeling.

> Experts agree that it is primarily the school which imposes the mentally retarded label and concommitant stigmatization on children, either initially or later on through a change in educational assignment. This follows from the fact that the school constitutes the first social institution in which the child comes into contact. PARC v. Commonwealth of Pennsylvania, 343 F. Supp. 279, 295 (E.D. Pa. 1972).

Second, educators at each level reinforce the stigma by rationalizing their own justifications for its existence. For example, a study of the University of California undergraduate and graduate programs, found a consistent pattern distinguishing faculty who had never dealt with

disabled students or colleagues, and those who had. Faculty who had never worked with disabled students:

> mentally experimented with the performance of their daily activities by asking themselves whether they could perform this or that task without hearing or sight or use of their limbs or voice. Encountering enormous imaginary problems in their mental experiments, respondents commonly concluded that their imagined problems accurately reflected the real difficulties and limitations of disabled people. D. Finnegan, Disabling For Disabled: Discrimination In Higher Education 8, Berkeley (1979).

These faculty simply rationalized their faulty assumptions and failed to recognize the myriad of systems disabled people develop to minimize the functional limitations imposed by their disabilities.[3]

---

3. For the blind, for example, numerous (footnote cont'd)

As employment opportunities for blacks were limited by the perception that they were "animal" in their "inclinations" and intellectually inferior, and as women were excluded from the mainstream of the labor force because their destiny was to produce and care for healthy offspring, so too have disabled people been barred from employment because of society's biased perceptions. One author has summarized the perceptions that employers, and others, have held of disabled job applicants as follows:

> (a) the Subhuman Organism, (b) The Menace, (c) the Unspeakable Object of Dread, (d) the Object

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technologies exist which make reading possible, e.g., Kurtzweile reading machine (reads printed material aloud), Opticon (converts print into vibrations), and public and private libraries which convert print to Braille.

of Pity, (e) the Holy Innocent, (f) the Diseased Organism, (g) the Object of Ridicule, and (h) the Eternal Child. W. Wolfsenberger, The Principle Of Normalization In Human Services, 16-24 (1972).

Given these perceptions, there is little wonder that people with disabilities remain unemployed regardless of numerous studies reflecting the economic benefits of hiring people with disabilities and the relative inexpensiveness of supplying any necessary accommodations. U.S. Civil Service Commission, A Chain of Cooperation: Severely Physically Disabled Employees in the Federal Service, 3 (1976). The positive benefits of employing racial minorities and women were similarly dismissed as irrelevant when it was socially and legally acceptable to base employment

decisions on the race or sex of the applicant.

The discriminatory nature of policies and practices which exclude and segregate disabled people has been obscured by the unchallenged equation of disability with incapacity and by the gloss of "good intentions." The innate biological and physical "inferiority" of disabled people is considered self-evident. This "self-evident" proposition has served to justify the exclusion and segregation of disabled people from all aspects of life. The social consequences which have attached to being disabled often bear no relationship to the physical or mental limitations imposed by the disability. For example, being paralyzed has meant far more than being

unable to walk--it has meant being excluded from public school,[4] being denied employment opportunities,[5] and being deemed an "unfit" parent.[6]

Both case law and legislation reflecting professional attitudes toward people with disabilities paralleled case law and legislation affecting the civil rights of women and of racial minorities. In Plessy v.

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4. "Many of the physically handicapped children do have the mental ability to attend public school but are denied that right due to architectural barriers and/or transportation problems." 117 Cong. Rec. 42293 (1971).

5. 13 Spectrum, at 29-32.

6. "Historically, child-custody suits almost always have ended with custody being awarded to the non-disabled parent, regardless of whether affectional or socio-economic advantages could have been offered by the disabled parent." 1 Vash, The Psychology of Disability 155 (1981).

Ferguson, 163 U.S. 537 (1896), this court sanctioned segregation by referring to the Court's limited role in altering what was commonly accepted as the need to separate the races. Following Plessy, Jim Crow legislation extended to every feature of southern public life. H. Horowitz, K. Karst, Law, Lawyers And Social Change 129-30 (1969). Also see C.V. Woodward, The Strange Career Of Jim Crow (3d Rev. ed., 1964).

Similarly, beliefs about women's limited roles resulted in protective legislation. The legislation and the stereotypes on which they were based were reinforced by judicial decisions.

> That woman's physical structure and the performance of maternal functions place her at a disadvantage in the struggle for subsistence is obvious. ...

> continuance for a long time on her feet at work, repeating from day to day, tends to injurious effects upon the body, and as healthy mothers are essential to vigorous offspring, the physical well-being of woman becomes an object of public interest and care in order to preserve the strength and vigor of the race... Muller v. Oregon, 208 U.S. 412, 421-22 (1908).

Thus, when women entered the work force, they had limited opportunities. Those who were employed worked in jobs that were extensions of their household work (e.g., laundries, clothing and textile factories).

Although the number of women in the work force increased during the 20th century (20% of all women were working in 1900; 25% in 1940 and 43.8% in 1972), see The Economic Role of Women in 1973 Economic Report Of The President 91, reprinted in Hearings on

Economic Problems of Women before the Joint Economic Committee, 93rd Cong., 1st Sess. 6 (1973), most women still did not obtain professional positions. For example, in 1950, 6.7% of all physicians were women. In 1970, only 9.3% of all physicians were women. Only 22.4% of all college and university teachers were women in 1950; in 1970, 28.6%. Supplement to the 1973 Economic Report Of The President, supra at 155-159.

Blacks encountered similar barriers. Racial prejudice and discriminatory hiring and promotion practices accounted for the lack of equal employment opportunity. But even when discriminatory motives were not present, the effects of segregation and inferior education resulted in

increased barriers in securing jobs. See Hearings before House Subcommittee No. 5 of the House Judiciary Committee on H.R. 7152, 88th Cong. 1st Sess. 1780 (Statement of George Meany, President, AFL-CIO).

Black employees were "largely relegated to 'unskilled and semi-skilled jobs'" and, because the number of such jobs was rapidly decreasing due to automation, "the relative position of the Negro worker [was] steadily worsening." United Steelworkers, Etc. v. Weber, 443 U.S. 193, 204 (1979), citing 110 Cong. Rec. 6548 (1964), (remarks of Sen. Humphrey).

Each of the three groups has sought relief from discrimination in the courts and in Congress. Blacks were the first to succeed in Brown and

its companion case, Bolling v. Sharp, 347 U.S. 497 (1954).

Over fifteen years after Brown, analogous equal protection arguments were made with respect to mentally retarded children in PARC v. Commonwealth of Pennsylvania, supra, Mills v. Board of Education of the District of Columbia, 348 F. Supp. 866 (D.D.C. 1972), and Wyatt v. Stickney, 325 F.Supp. 781 (M.D. Ala. 1971). Each of these landmark decisions cited this Court's decision in Brown to support their holdings that disabled children were entitled to a public education to the same extent as their nondisabled peers.

Congress enacted the Civil Rights Act of 1964 to hasten desegregation efforts. The legislation adopted

several different approaches, including the prohibition, in Title VI of the Act, of discrimination on the basis of race, color, or national origin by recipients of federal funds. 42 U.S.C. §2000d et seq.

Women, following the example of the black civil rights efforts, sought redress by Congress and in the courts for discrimination. In education, Congress' response was embodied in Title IX of the Education Amendments of 1972, 20 U.S.C. §1681, et seq. which prohibited discrimination in education on the basis of sex by recipients of federal funds. Congress based Title IX on Title VI in recognition of the similar types and effects of discrimination on both groups.

In employment, Congress found that

"an entire segment of our society is forced into a condition of marginal existence" because of racism that was the inevitable result of stigmatizing stereotypes. H.R. Rep. No. 914, 88th Cong., 1st Sess. 28 (1963) as reprinted in 1964 U.S. Code Cong. & Ad. News 2391. To combat this problem Congress enacted Title VII of the Civil Rights Act of 1964, 42 U.S.C. 2000e et seq., which prohibited practices of discrimination on the basis of race, color, sex, religion or national origin by private employers, employment agencies, and labor unions. Congress expanded and strengthened Title VII in enacting the Equal Employment Opportunity Act of 1972. Pub. L. 92-261.

This court has recognized that

Title VII was

> intended as a spur or catalyst to cause employers and unions to self-examine and to self-evaluate their employment practices and to endeavor to eliminate, so far as possible, the last vestiges of an unfortunate and ignominious page in this country's history. Albemarle Paper Co. v. Moody, 422 U.S. 405, 418 (1975).

This court has also noted that:

> Before the Civil Rights Act of 1964 was enacted, an employer could fashion his personnel policies on the basis of assumptions about the differences between men and women, whether or not the assumptions were valid.
>
> It is now well recognized that employment decisions cannot be predicated on mere 'stereotyped' impressions about the characteristics of males or females. City of Los Angeles, Department of Water and Power v. Manhart, 435 U.S. 702, 707, (1978).

Congress, in enacting Section 504 of the Rehabilitation Act of 1974 recognized that while there were major

physical and mental variations in different disabilities, disabled people as a group faced similar discrimination in employment, education and access to society. As stated in the Senate Report accompanying the 1974 amendments to the 1973 Act:

> Section 504 was enacted to prevent discrimination against all handicapped individuals,...in relation to federal assistance in employment, housing, transportation, education, health services, or any other Federally-aided program. S. Rep. No. 1297, 93rd Cong. 2d Sess. 38, reprinted in 1974 U.S. Code Cong. & Ad. News 6373, 6388.

Disabled children's right to equal educational opportunity has also been established by Congress' enactment of PL 94-142: The Education for All Handicapped Children Act of 1975, 20 U.S.C. §1401 et seq.[7] As with Title VI of the Civil Rights Act of 1964 and

Title IX of the Education Amendments of 1972, the Congress intended that all children, regardless of race, or sex or the severity of disability, be provided a free appropriate public education and thereby reversed decades of discrimination that had been based on the professional opinions of educators who had, knowingly or not, incorporated unfounded stereotypes about each of these groups into their work.

The bases for the stereotypes about racial minorities and women are considered deplorable today. While stereotypes about people with

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7. PL 94-142 represents the culmination of trends towards increased federal involvement in the education of disabled chidren. A significant bulk of the requirements set out in PL 94-142 had already established in PL 93-380 (Education of the Handicapped Amendments of 1974).

disabilities are similarly outrageous, public attitudes have not yet caught up with Congress's recognition of that fact, as evidenced by this case.

As the next section demonstrates, health care professionals are not immune from stereotypical assumptions about people with disabilities. Furthermore, they were not immune from stereotypes about women and racial minorities, and they provided "scientific" bases that strengthened and perpetuated many of the stereotypes.

II. In the Context of Health Care, Stereotypes About Racial Minorities, Women And People With Disabilities Have Resulted In Similar Manifestations Of Discrimination And Have Been The Subject Of Similar Legislation

Throughout history, being

"handicapped has defined the role and the needs of people with disabilities.

> All political, legal, and ethical issues [have been] transformed into questions of disease and death, deviance and normal adjustment, proper and improper management of the disability. Gliedman and Roth, supra at 300.

As a result, the kind of health care that people with disabilities have been able to obtain has at times depended more on society's perception of the disabled as sick, and, therefore, inferior, than it has on the individual's specific health care needs.

Similarly, the view that black diseases resulted from the physical inferiority of the race, or from a divine plan for its extinction, were antithetical to any effort to understand the unique health

difficulties of blacks, and to determine their different nutritional requirements. Kiple, supra at 202-203.

Discrimination against women in health care was rooted in the analogous belief that women were physically inferior to men:

> To doctors [in the nineteenth century], women were so different from men as to constitute a sub-species. Corea, The Hidden Malpractice: How American Medicine Treats Women As Patients And Professionals 88 (1977).

For each of the three populations, sickness, and the concomitant need for medical care, was ascribed to the innate inferiority of the patient. In other words, the patient's state of health was always measured against the "normal", to wit, the white man. This approach permitted society to ignore

the miserable environmental conditions in which racial minorities lived. The epidemics of tuberculosis, pneumonia, and syphilis, as well as disproportionately high rates of still births and infant mortality, were ascribed to the failures of the patients themselves. Kiple, supra at 188.

Before the Civil War, the poor health conditions of blacks provided an additional rationale in support of slavery. It was thought that

> the unhappy physical and mental state of the Blacks made it imperative that a superior race direct and take care of them.

Kiple, supra at 180-181. Following the Civil War, Southern physicians, swayed by the new theories of Charles Darwin, justified white racism on "scientific"

grounds:

> The medical journals of the period almost bristle with writings of doctors eager to portray the black as a filthy, loathsome, disease-ridden creature who was not only a threat to himself and his own people but an epidemiologic menace to whites as well. For them the plight of the blacks was the result of "some supreme law... Id. at 189.

Women, too, suffered from this "blame theory" of medicine. If women became sick, it was because women were "inherently defective" Ehrenreich and English, Complaints and Disorders: The Sexual Politics of Sickness in Seizing Our Bodies: The Politics Of Women's Health 44 (C. Dreifus, ed. 1977). Headaches and nervous disorders were "linked with malfunctioning female sexual organs" A. Wood, "The Fashionable Diseases": Women's

Complaints and Their Treatment in Nineteenth-Century America in Women And Health Care In America-Historical Readings, supra at 223, as were all other medical complaints.

> Physicians saw woman as the product and prisoner of her reproductive system ... it was the cause of her most common ailments; woman's uterus and ovaries controlled her body and behavior from puberty through menopause. Rosenberg, supra at 13.

One consequence of this belief was women were also blamed for their illnesses if they abandoned "feminine pursuits" and behaved in contradiction to biological imperatives.

> ladies get sick because they are unfeminine--in other words, sexually aggressive, intellectually ambitious and defective in proper womanly submission and selflessness. Wood, supra at 227 (emphasis in the original).

People with disabilities have not been immune from the "blame theory" of medicine, both for their own illnesss and for creating health problems for society, as well.

> [Feeblemindedness] is responsible ... for the majority of cases of chronic and semi-chronic pauperism, and for much of our alcoholism, prostitution, and venereal diseases. L.M. Terman, Feeble-Minded Children in the Public Schools of California, 5 Schools and Society 161 (1971), cited in City of Cleburne v. Cleburne Living Center, U.S. , slip at 7, n.9 (1985)(Marshall, J., concurring and dissenting).

The solutions that society developed for eliminating the health menaces presented by racial minorities, by women, and by people with disabilities have been strikingly similar. Believing that blacks were at a lower evolutionary stage than whites,

some doctors argued for a hastening of the evolutionary extinction process through the sterilization of the entire black male population by vasectomy, a solution which would "bravely and humanely [solve] the greatest race problem of the ages." Kiple, supra at 189.

The same approach was used in the nineteenth century to correct, both medically and morally, women's health problems. Cures for women's diseases were:

> designed both as a punishment and an agent of regeneration for they forced [her] to acknowledge [her] womanhood. Ehrenreich and English, supra at 227.

For example, removal of both ovaries was frequently performed in the nineteenth century to cure feminine nonconformity--which included

"neurosis, troublesomeness, eating like a plowman, ... attempted suicide, erotic tendencies" among other deviant behaviors. Corea, supra at 95.

At the turn of this century, it was widely believed that if those with mental or physical disabilities were castrated or segregated, the source of all future social problems would disappear. R. Burgdorf, M. Burgdorf, The Wicked Witch is Almost Dead: Buck v. Bell, 50 Temple L.Q. 995, 997 (1977). When, in the 1890s, vasectomies and salpingectomies (cutting or removal of the fallopian tubes) were developed, the Indiana State Reformatory for the Mentally Retarded sterilized between 600 and 700 boys. Other similar institutions followed suit. Id. In 1907, the

Indiana Legislature enacted a sterilization statute, as did 28 other states by 1930. Id.

A major advance in the civil rights of racial minorities, women, and people with disabilities, in the health care context, came with the development of the principle of informed consent. Before that theory became firmly established, all three populations were at the mercy of "treatments" and medical experiments. For example, the Tuskegee experiments conducted between 1932 and 1972 by the United States Health Service, demonstrated the degree to which racism affected the medical profession. Some 400 black patients who had applied for treatment for syphilis went untreated so that the "natural history" of the disease could

be observed. Over 100 of these patients died. J. H. Jones, Bad Blood: The Tuskegee Syphilis Experiment 50 (1981).

Nor did women participate in decisions about their medical treatment. Male doctors, especially in the nineteenth century, "preferred to keep women in ignorance" Wood, supra at 228). As one Philadelphia physician wrote:

> Wise women chose their doctors and trust them. The wisest ask the fewest questions. Mitchell, Doctor and Patient (1888), 48, quoted in Wood, supra at 228.

For people with disabilities, the result of the segregation theories, some based on the need to protect society from the disabled and others based on the disabled's need to be protected from society, Spectrum, supra

at 32-35, was the creation of large, closed institutions. Once inside the institutions, the physically disabled, mentally retarded, and mentally ill became the subjects of medical experiments, of psychotropic drug therapy, electroconvulsive therapy, psychosurgery, and aversive behavioral therapies--all in the absence of informed consent. Id. In addition, they became "an easily exploited source of organ transplants." Id. at 36.

The most publicized example of research involving the institutionalized mentally retarded was the hepatitis experiment at the Willowbrook State School in New York. In an attempt to develop a vaccine for the disease, researchers infected otherwise healthy children, many of

whom became seriously ill.[8] Like the infamous Tuskegee experiment, see supra at ____, the researchers took advantage of their subjects because of their "easy availability, their compromised position, and their manipulability." Id.

In other words, women, racial minorities, and people with disabilities suffered at the hands of a profession which reflected prevalent social and political attitudes. Medical standards of care were defined

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8. Litigation challenging this "experiment" resulted in a court-approved consent decree prohibiting medical experimentation, New York State Association for Retarded Children v. Rockefeller, 357 F.Supp. 752 (E.D.N.Y. 1973) as reported in Report and Recommendations of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 43 Fed. Reg. 11328, 11345-51 (March 17, 1978).

by an image of the nondisabled, white, male patient. For one reason or another, the medical profession treated women, racial minorities and the disabled according to some lesser standard that better suited the perceived inadequacies of the group as a whole. The medical profession itself has recognized this fact.

For example, infants born with disabilities who have been subjected to different medical standards from those applied to nondisabled newborns are a prime example of this phenomenon. The clearest explanation for this fact comes from surveys of physicians. In studies conducted in 1975, 1976, 1977, and 1982, the majority of physicians responded that they would not act to save the life of a Down's Syndrome

child if the parents -- presumably after being counseled by the same doctors -- agreed not to have a life-saving procedure performed. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Decisions to Forego Treatment 208, fns. 46, 47, 48, 49 and accompanying text. One of the studies found that, apart from parental desires, "59% of the pediatricians surveyed in Massachusetts would not recommend surgery for a Down's Syndrome infant with intestinal blockage." Id., fn. 48.

A study showing that "pediatricians were significantly more pessimistic about the ultimate abilities of mentally retarded adults

than psychologists and educators," suggested that the differences among the professionals resulted from the pediatricians' lack of education. Wolraich and Siperstein, Assessing of Professionals' Prognostic Impressions of Mental Retardation, 21 Mental Retardation 8 (February 1983). "Pediatric training typically involves minimal exposure to mental retardation," (Task Force on Pediatric Education, 1978). Id. at 10.

Congress has been well aware that the medical profession is not immune from prevailing stereotypes and has acted to assure that bias does not result in discriminatory treatment. The primary avenue of attack on racial discrimination in health care facilities has been Title VI of the

Civil Rights Act of 1964. In fact, discrimination in health care was one of the reasons that Congress enacted Title VI. See, e.g., 110 Cong. Rec. 7054 (1964)(remarks of Sen. Pastore).

In 1965, HEW issued its first set of regulations interpreting Title VI. 45 CFR Part 80. The regulations prohibit not only discriminatory denial of treatment, but any form of differential or segregative treatment based on race, color, or national origin. 45 CFR §80.3(b)(1). They also prohibit facially nondiscriminatory policies which have the indirect effect of subjecting individuals to discrimination through, for example, criteria or methods of administration, or through site location for facilities. 45 CFR §80.3(b)(2).

Consistent with the Title VI regulations, HEW published §504 regulations which include a specific section on prohibited practices in health care. 45 CFR Part 84, Subpart F.

Title VI, Section 504, and Title IX have been successful in addressing many of the barriers faced by women, racial minorities, and people with disabilities. As a result of these statutes, and of supportive judicial decisions, society's attitudes toward members of these three groups have had the opportunity to evolve toward theories of pluralism and away from stigmatizing stereotypes. The medical profession, like all other professions, has recognized the role that public attitudes have played in medical

decisionmaking. One author specifically noted the impact of Section 504 and P.L. 94-142 on medical decisions with regard to disabled newborns, after reciting findings that substantially more disabled newborns are helped to survive than was true four years before.

> Social change is another likely explanation for the increased frequency with which parents have asked for early surgical treatment of an infant, despite a poor prognosis... Perhaps parents are less likely to be deterred...by the prognosis for disabilities (wheelchair mobility and intellectual limitation) in an era when it is more acceptable for a disabled person to remain in the community. J. McLaughlin, et al., Influence of Prognosis on Decisions Regarding the Care of Newborns With Myelodysplasia, 312 N.E.J. of Med. 1589(6/20/85).

III The Protections of Section 504, Like the Protections of Title VI, Apply At Birth

One of the questions presented in this case is whether Section 504 applies at birth. There is nothing in the literal language of the statute to suggest otherwise.[9] Nor is there anything in the legislative history of Section 504, or of Title VI, on which Section 504 is based,[10] to suggest otherwise.

The legislative history of Section 504 reflects the fact that Congress intended the statute to cover discriminatory health practices for all patients. See Statements of

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9. "No otherwise qualified individual in the United States. ..." 29 U.S.C. 794.

10. See Community Television of Southern California v. Gottfried, U.S. , 103 S.Ct. 885, 892 (1983). Other amicus briefs develop the legislative history of Section 504.

Congressman Vanik, 117 Cong. Rec. 45974 (1971), and Senator Humphrey, 118 Cong. Rec. 525, 9495, 9499, 9500 (1972). Further, as is more fully developed in other briefs, the Congress modeled Section 504 on Title VI, and intended their coverage to be consistent. See Alexander v. Choate, 105 S.Ct. 712 (1985).

The administrative history of Title VI clearly reflects that the Department of Health, Education and Welfare understood that Congress intended Title VI to be enforced to protect newborns from discrimination. Soon after Title VI was enacted, HEW surveyed hospitals throughout the country. The survey instrument was called the "Medical Facilities Compliance Report" and it asked

questions about every area of the hospital, including nursery facilities.

HEW also published "Guidelines for Compliance With Title VI of the Civil Rights Act of 1964" shortly after the enactment of Title VI, to assist hospitals in bringing their facilities into compliance. See L. Terry, Hospitals and Title VI of the Civil Rights Act, 39 Hospitals, Journal of the American Hospital Association (Aug. 1, 1965). The Guidelines state at the outset that:

> Hospitals in compliance with the Act are characterized by absence of separation, discrimination or any other distinction on the basis of race, color, or national origin in any activity carried on, in, by or for the institution affecting the care and treatment of patients.

The Guidelines elaborate by prohibiting discrimination in the provision of any

treatment, to any patient.

Finally, HEW successfully prosecuted hospitals for failing to desegregate their delivery rooms and nurseries. See, In the Matter of Board of Trustees of State Eleemosynary Institutions, Natchez Charity Hospital, et al., Docket No. MCR-59, Administrative Proceeding in the Department of Health, Education and Welfare (1/13/69). As a result of this administrative hearing, HEW terminated federal financial assistance to the three named hospitals.[11]

If Section 504 is to be applied in a manner consistent with Title VI, as

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11. In judicial litigation, HEW enforced Title VI for all hospital patients. See, e.g., Bryan v. Koch, 627 F.2d 612 (2d Cir. 1980).

the Congress intended, then it follows that the protections of Section 504 apply at birth.

Conclusion

Theories about the inherent limitations and weaknesses of women, racial minorities, and the disabled have fueled discrimination against the three groups. The blatancy of gender and race discrimination has faded as laws and judicial decisions have reflected and spurred changes in attitude. Attitudes toward people with disabilities are often still reminiscent of the race and gender attitudes of eighty years ago.

In 1973, Congress based Section 504 on Title VI and Title IX. It did so to address discrimination in the

same way, and for the same reasons, that it had chosen to address discrimination in the earlier statutes.

This Court has applied Section 504 to hold that people with disabilities are entitled to work, Consolidated Rail Corporation v. Darrone, ___ U.S. ____, 104 S.Ct. 1248 (1984) and to have meaningful access to medical care, Alexander v. Choate, supra. This Court has relied on the Constitution to find that people with disabilities are entitled to live in the community, City of Cleburne v. Cleburne Living Center, supra and it has relied on P.L. 94-142 to find that students with disabilities are entitled to be educated with their non-disabled peers, Board of Education v. Rowley, 458 U.S. 176 (1982). Without the right to discrimination-

free medical decisions at birth, the rights to education, work, housing, and medical care become meaningless. Respondent's authority to regulate in this area is consistent with the decisions of this Court and with the administrative history of Section 504.

For the foregoing reasons, Amicus respectfully submit that the Court reverse the decision below.

Respectfully submitted,
CENTER FOR LAW AND SOCIAL POLICY

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No. 84-1529

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Petitioner,
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Respondents.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

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Respondents.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF OF THE RUTHERFORD INSTITUTE, THE RUTHERFORD INSTITUTE OF ALABAMA, THE RUTHERFORD INSTITUTE OF GEORGIA, THE RUTHERFORD INSTITUTE OF MINNESOTA, THE RUTHERFORD INSTITUTE OF MONTANA, THE RUTHERFORD INSTITUTE OF TENNESSEE, THE RUTHERFORD INSTITUTE OF TEXAS, AND THE RUTHERFORD INSTITUTE OF VIRGINIA, AMICI CURIAE, IN SUPPORT OF THE PETITIONER

INTEREST OF AMICI CURIAE*

This case presents important issues concerning the rights of handicapped newborn infants to receive needed

*Counsel of record to the parties in the case described above have consented to the filing of this brief and letters of consent have been filed with the Clerk pursuant to Rule 36.

medical treatment in the face of "private" choices and social pressures to withdraw such treatment for reasons of inconvenience, social cost or quality of life. The Rutherford Institute is opposed to the passive euthanasia of "inconvenient" young life and to the treatment of handicapped infants as chattel, without regard to constitutional rights of due process of law. The Rutherford Institute believes that the Congress, by enacting Section 504 and related provisions, evinced a clear intent to formulate a broad national policy to prohibit all discrimination against all handicapped persons in connection with any Federally funded programs and activities. This broad proscription includes discrimination in medical treatment decisions involving handicapped newborn infants receiving health services at Federally funded hospitals. The Rutherford Institute believes that the decision of the Court of Appeals should be rejected as inconsistent with the statutory language and legislative history of Section 504.

Amici Curiae are non-profit religious corporations named for Samuel Rutherford, a 17th-century Scottish minister and Rector at St. Andrew's University. With state chapters in Alabama, Georgia, Minnesota, Montana, Tennessee, Texas and Virginia and its national office in Manassas, Virginia, The Rutherford Institute undertakes to assist litigants and to participate in significant cases relating to the protection and safeguarding of human life. Counsel for *amici curiae* have specialized in litigation in state and federal courts and have participated as counsel for *amici curiae* in previous cases before this Court. The Rutherford Institute believes the expertise of its counsel will be of assistance to the Court in this case.

STATEMENT OF FACTS

Amici curiae adopt by reference the statement of facts as set forth in Petitioner's brief filed with this Court.

SUMMARY OF ARGUMENT

On its face, Section 504 of the Rehabilitation Act of 1973 is a broad proscription against handicap discrimination under any Federal program or activity. Because the proscription goes beyond mere "exclusion from participation" or "denial of benefits" and extends to any handicapped person that is "subjected to discrimination," the plain language of the statute suggests that the Congress intended to reach any and all discrimination, not merely discrimination involving "access" to Federal programs. Moreover, it is clear that handicapped newborn infants are "otherwise qualified handicapped individuals" within the meaning of Section 504 when they (1) meet all relevant requirements, if any, to obtain natal or post natal medical treatment offered in connection with a Federal program or activity (*Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979)) and (2) are "excluded from participation" or "denied benefits" or "subjected to discrimination" under any such program or activity.

The legislative history of Section 504, from its enactment in 1973 through amendments in 1974 and 1978, indicates that the Congress intended to establish "a broad government policy that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap." S. Rep. No. 1297, 93d Cong. 2d Sess., *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6390 [hereinafter "S. Rep. No. 1297"]. Moreover, as a matter of public policy, the Congress also clearly expressed its concern about "the denial of basic rights of individuals with handicaps" and with the need

to provide new mechanisms to insure "diagnosis, evaluation and treatment early in a child's life." *Id.* at 6406–6407. As this Court recently recognized, the 1974 amendments, expanding the scope of Section 504, clarified that those "charged with administering the Act had substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*_U.S._(January 9, 1985), Slip Op. at 16, n. 24.

Finally, the legislative history is explicit that Section 504 was to have the same reach as Section 601 of the Civil Rights Act of 1964 and Section 901 of the Education Amendments of 1972. S. Rep. No. 1297 at 6390. These latter provisions have a broad reach, extending, for example, in the case of Section 601 of the Civil Rights Act of 1964, "to assure that hospitals financed by Federal money would not deny *adequate* care to Negroes." 110 Cong. Rec. 1519 (January 31, 1964) (emphasis supplied). Section 504 was intended to have the same broad sweep with respect to the handicapped.

ARGUMENT

The question presented in this case, as in *United States* v. *University Hospital, State University of New York*, 729 F.2d 144, 150 (2nd Cir. 1984), is solely one of statutory construction, to wit: Did Congress intend for Section 504 of the Rehabilitation Act of 1973 to reach alleged discrimination in the treatment of handicapped newborn infants, solely because of their handicaps?

In attempting to discover the legislative intent, the lower courts have relied principally on the lack of any clear statement by the Congress that Section 504 would be used to monitor medical treatment of so-called "defective" newborns. *See id.* at 159-160; *American Acad-*

emy of Pediatrics v. *Heckler*, 561 F. Supp. 395 (D.D.C. 1983). This reliance is misplaced. As a matter of statutory interpretation, it is not necessary that the Congress consider or approve every conceivable application of a statute for it to be given its intended effect. Justice Holmes, in a decision written as Circuit Justice, described the error in the approach taken by the lower courts:

> A statute may indicate or require as its justification a change in the policy of the law, although it expresses that change only in the specific cases most likely to occur to the mind. The Legislature has the power to decide what the policy of the law shall be, and if it has intimated its will, however indirectly, that will should be recognized and obeyed. The major premise of the conclusion expressed in a statute, the change of policy that induces the enactment, may not be set out in terms, but it is *not* an adequate discharge of duty for courts to say: We see what your are driving at, but you have not said it, and therefore we shall go on as before.

Johnson v. *United States*, 163 F. 30, 32 (1st Cir. 1908) (emphasis supplied). The proper rule of interpretation, to paraphrase Justice Holmes, is: We see what you are driving at, and what you have said, and we shall give it effect, absent any indication that it was not intended to have such an effect. *Cf. United States* v. *Bramblett*, 348 U.S. 503, 507 (1955), *cited* in *Huddleston* v. *United States*, 415 U.S. 814, 825 (1974) ("There is no indication in either the committee reports or in the congressional debates that the scope of the statute was to be in any way restricted.").

The analysis must begin with the language of the statute. *Southeastern Community College* v. *Davis*, 442 U.S. 397, 405 (1979). It is also necessary to review the legislative history to discover and give effect to the legislative intent, for

> A thing may be within the letter of a statute and not within its meaning, and within its meaning though not within its letter. The intention of the lawmaker is the law.

Smythe v. *Fiske*, 23 Wall. 374, 380 (1874), *cited* in *Hawaii* v. *Mankichi*, 190 U.S. 197, 212 (1903).

A. The Statutory Language.

Section 504 of the Rehabilitation Act of 1973 provides, in relevant part:

> No *otherwise qualified handicapped individual* in the United States, as defined in Section 706(7) of this title, *shall, solely by reason of his handicap,* be *excluded from* the *participation* in, be *denied* the *benefits* of, or be *subjected to discrimination under any program or activity* conducted by any Executive agency or by the United States Postal Service (emphasis supplied).

29 U.S.C. Section 794. Section 7(b) of the Act defines the term "handicapped individual" to mean:

> . . . any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

29 U.S.C. Section 706(7)(B).

On its face, Section 504 broadly prohibits discrimination—whether by exclusion, denial of benefits or other

disparate treatment—under any Federal program or activity. The statutory language suggests that the Congress was concerned with more than simple "access" to Federal programs, because a ban on exclusion or denial of benefits would have remedied most, if not all, "access" discrimination. However, Congress went further to require that no handicapped individual shall be "subjected to discrimination" under any Federal program or activity, thereby expanding the plain reach of the statute to cover discrimination occurring in the day-to-day operations of Federally funded programs and activities.

The principal question as to the language of the statute centers on the term "otherwise qualified handicapped individual" and whether a handicapped newborn infant falls within this class of persons. The question is two-fold: Is a handicapped newborn infant a "handicapped individual" and, if so, is such an infant "otherwise qualified" within the meaning of the statute?

Despite the Second Circuit's painstaking analysis of the first part of this question in the *University Hospital* case, it properly concluded that "it would defy common sense to rule that she [Baby Jane Doe] is not presently *regarded* as handicapped under Section 706(7)(B)(iii)." 729 F.2d at 155 (emphasis in original). To dispel any doubt on this question, however (and, indeed, to ask why the Second Circuit even gave pause to this question), it is helpful to review the unequivocal language of the Senate Committee Report concerning the extended reach of Section 504 under the new statutory definition:

> The amended definition . . . takes cognizance of the fact that handicapped persons are discriminated against in a number of ways . . . .
>
> Clause [i] in the new definition . . . makes the definition applicable to the provision of

> Federally-assisted services and programs. Clause [ii] is intended to make clearer that the coverage of Section 503 and 504 extends to persons who have recovered—in whole or in part—from a handicapping condition, . . . but who may be discriminated against or otherwise be in need of the protection of Section 503 and 504.
>
> Clause [iii] in the new definition clarifies the intention to include those persons who are discriminated against on the basis of handicap, whether or not they are in fact handicapped, just as title VI of the Civil Rights Act of 1964 prohibits discrimination on the ground of race, whether or not the person discriminated against is in fact a member of a racial minority. *This subsection includes within the protection of Sections 503 and 504 those persons who do not in fact have the condition which they are perceived as having, as well as those persons whose mental or physical condition does not substantially limit their life activities and who are thus not technically within clause [i] in the new definition.* Members of both of these groups may be subjected to discrimination on the basis of their being regarded as handicapped.

S. Rep. No. 1297 at 6389–6390 (emphasis supplied). The definition of "handicapped individual" was thus intended to reach discrimination against *all* handicapped people as well as *all* who discriminate on the basis of handicap, whether or not a handicap actually exists.

The Second Circuit was also troubled as to whether a handicapped infant was an "otherwise qualified" handicapped individual, within the meaning of the statute.

Relying on this Court's decision in *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979) (denial of admission to educational program) and the Second Circuit's decision *Doe* v. *New York University*, 666 F.2d 761 (2d Cir. 1981) (same), the *University Hospital* panel majority found that "otherwise qualified" had meaning only in the context of "static" programs or activities such as education, employment or transportation, and not in the comparatively "fluid" context of medical treatment decisions. 729 F.2d at 156. To hold otherwise, the majority concluded, would distort what the majority perceived to be the statute's "plain meaning":

> In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents.

Id. This tortured interpretation is, at best, a "straw man" begging to be knocked down. The panel majority errs by focusing on the purported remedy to discrimination—i.e., corrective surgery or litigation to obtain it. However, the legislative history of Section 504 and this Court's decisions interpreting Section 504 make clear that the proper focus is on the requirements, if any, for infants to participate or receive benefits in the relevant Federal program or activity.

At the time Section 504 was drafted, it was aimed strictly at employment and vocational rehabilitation. See Part B *infra*. In that context, there were obvious eligibility requirements (independent of handicap) to participate in or receive benefits in connection with programs and activities related to employment or vocational rehabilitation. *Cf. Southeastern Community College* v.

Davis, 442 U.S. 397 (1979). The 1974 amendments, however, extended the reach of the Act beyond jobs and education to housing, transportation, health services and all other Federally aided programs. The term "otherwise qualified" in the context of these programs has less or no significance because there are few, if any, requirements to participate in or receive benefits other than the handicapping condition itself.

Unlike the situation presented in the *Davis* case, which involved the educational context, medical treatment for a newborn infant suffering from multiple birth defects, offered in conjunction with a Federal program, is not offered independent of the handicap, but rather is offered solely *because of the handicap*. Since the Congress obviously intended to prohibit handicap discrimination in the provision of health services, it would be incongruous to *impose* artificial requirements to qualify for such services when such an interpretation would emasculate the statute. It would likewise be nonsensical to hold that the statute does not apply to handicapped newborn infants because of the *absence* of particular qualifications for treatment independent of the handicap.*

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*In *United States* v. *Baylor University Medical Center*, 736 F. 2d 1039 (5th Cir. 1984), the United States Court of Appeals for the Fifth Circuit held that receipt of Medicaid and Medicare payments constituted "federal financial assistance" for purposes of Section 504 and that Section 504 was violated when a hospital refused to allow a deaf patient to bring an interpreter into the hospital to understand her pre- and post-operative discussions with the medical staff. Under the reasoning of the *University Hospital* panel majority, however, the hospital would not be in violation of Section 504 if it simply refused to treat any condition of the woman which was related to her handicapping condition (i.e., deafness). Section 504 is a flimsy right, indeed, if, once a deaf person or handicapped infant walks through the hospital door, they can be denied the very treatment which would allow them to fully function as citizens, merely because Section 504 allegedly does not apply to "medical treatment" decisions relating to their handicap.

It is more reasonable to conclude that Congress intended for the meaning of "otherwise qualified" to depend on the context of the Federal program or activity involved. "Otherwise qualified" handicapped individuals are thus handicapped individuals (i) who are able to meet all of the requirements, *if any*, for participation in any program or activity which is funded by the Federal government, in spite of their handicap (*Southeastern Community College* v. *Davis*, 442 U.S. at 406), and (ii) who are "excluded from participation," or "denied benefits" or "subjected to discrimination" under any such program or activity. Accordingly, handicapped newborn infants who receive medical treatment in connection with any Federal programs or activities are "otherwise qualified," provided that the hospital generally offers treatment of the type required by the infant. Likewise, the failure to exercise *bona fide* medical judgment in the administration of a program or activity involving infants qualified to receive Federally funded natal and post-natal care constitutes unlawful discrimination under Section 504.

B. The Legislative History.

Despite the clarity of the statutory language, it is necessary to review the legislative history of the statute to determine the legislative intent. In this regard,

> [i]t has never been questioned in this Court that Committee reports, as well as statements by those in charge of a bill or of a report, are authoritative elucidations of the scope of a measure.

Schwegmann Brothers v. *Calvert Distillers Corporation*, 341 U.S. 384, 399–400 (1951) (Frankfurter, J. dissenting). It is also helpful to "analyze the policies underlying the statutory provision to determine its proper scope." *Rose*

v. *Lindy*, 455 U.S. 509, 517 (1982). In this case, the relevant legislative history includes not only Section 504's genesis in 1973, but also its evolution by amendment in 1974 and 1978.

The Rehabilitation Act of 1973. The Rehabilitation Act of 1973 was enacted on September 26, 1973, to implement comprehensive changes in Federal-state vocational rehabilitation programs and was intended to replace the existing Vocational Rehabilitation Act. S. Rep. No. 1297 at 6376. The 1973 Act was aimed principally at employment of the handicapped as well as assisting the handicapped to function in society. S. Rep. No. 318, 93d Cong., 1st Sess., *reprinted in* 1973 U.S. Code Cong. & Ad. News 2076 [hereinafter "S. Rep. No. 318"]. Senator Dole, a co-sponsor of the Senate version of the Rehabilitation Act, discussed the general goals of the Act:

> The primary goal of this bill is to assist handicapped individuals in achieving their full potential for participation in our society. . . . I believe this bill will work to the real benefit of America's disabled. This bill contains the State plan requirements, the individualized written programs, strong emphasis on research and training, and antidiscrimination provisions.

119 Cong. Rec. 24589 (Daily ed. July 18, 1973). Because the President vetoed two previous bills, the Act was, in effect, a negotiated agreement between the Congress and the Administration. S. Rep. No. 318 at 2077–2078. An interagency and congressional dialogue on implementation of the new law immediately followed the bill's enactment. It soon became clear that "certain clarifying and perfecting changes would be required in order to permit the full implementation of Congressional intent." *Id.* at 6376–6377. As was acknowledged in *Consolidated*

Rail Corp. v. *Darrone*,_U.S._(February 28, 1984), Slip Op. at 7,

> [E]nhancing employment of the handicapped was so much the focus of the 1973 legislation that Congress the next year felt it necessary to amend the statute to clarify whether Section 504 was intended to prohibit other types of discrimination as well.

The 1974 Amendments. Amendments were prepared and passed by both houses of the Congress in 1974. The amendments were vetoed by President Ford, but the veto was overridden. S. Rep. No. 1297 at 6373–6374. This Court has recognized that the 1974 "amendments and their history . . . shed significant light on the intent with which Section 504 was enacted." *Alexander* v. *Choate*,_U.S._(January 9, 1985), Slip Op. at 18–19 n. 27.

The amendments substantially expanded the scope of the law relating to the handicapped, including Section 504:

> (1) Section 7(b) added a new definition of "handicapped individual" which affected numerous provisions of existing law, including Section 504, and extended the overall reach of the anti-discrimination statute beyond employment and vocational concerns;
>
> (2) Section 101(a)(6) provided for affirmative action for the handicapped by state agencies and facilities receiving Federal vocational aid; and
>
> (3) Section 101(a)(9)(c) provided for detailed record keeping with reference to such affirmative action.

S. Rep. No. 1297 at 6375. The amendments also authorized continuing appropriations for handicap programs, restructured administrative agencies for more effective implementation of handicap programs, provided for grants and special projects for special demonstration programs, and called for a White House Conference on Handicapped Individuals, with a clear mandate for investigation and study. *Id.* at 6374–6376.

Whereas in 1973 Section 504 applied only to handicapped individuals in the context of employment or vocational rehabilitation, the new definition of "handicapped individual" in 1974 greatly expanded the reach of Section 504 to include, in the words of the Senate Committee report, "*all* handicapped individuals, regardless of their need for, or ability to benefit from, vocational rehabilitation services, in relation to Federal assistance in employment, housing, transportation, education, *health services*, or any other Federally-aided programs." *Id.* at 6388 (emphasis supplied). The committee report further elaborated that:

> Section 504 was patterned after, and is almost identical to, the anti-discrimination language of Section 601 of the Civil Rights Act of 1964, 42 U.S.C. 2000d-1 (relating to race, color, or national origin) and Section 901 of the Education Amendments of 1972, 42 U.S.C. 1683 (relating to sex). *The section therefore constitutes the establishment of a broad government policy that programs receiving Federal financial assistance shall be operated without discrimination on the basis of handicap.*

Id. at 6390 (emphasis supplied). This legislative history is unequivocal and without reservation. Section 504 was intended to reach *all* handicapped people who participate in, receive benefits from or are discriminated against in

connection with Federal programs or activities and *all* who discriminate against such persons. *Cf. Atascadero State Hospital* v. *Scanlon*,_U.S._(June 25, 1985) (Brennan, J., dissenting).

The legislative history of the 1974 amendments is also important to the present inquiry for the public policy declared therein by the Congress. Contemporaneous declarations of public policy are useful aids in determining the meaning of a statute.

> It is well settled that, in interpreting a statute, the Court will not look merely to a particular clause in which general words may be used, but will take in connection with it *the whole statute* . . . and the objects and policy of the law . . . .

Brown v. *Duchesne*, 19 How. 183, 194 (1857) (emphasis supplied), *cited* in *Stafford* v. *Briggs*, 444 U.S. 535 (1980); *Rose* v. *Lundy*, 455 U.S. 509, 517-518 (1982).

The 1974 Senate Committee Report declared that "now more than ever a concerted and in depth examination must be made of all aspects of law and public policy which affect individuals with handicaps." S. Rep. No. 1297 at 6401. To this end, a call was issued for a White House Conference on Handicapped Individuals to identify problems and solutions for the handicapped. In doing so, the Senate Committee proceeded to make several declarations about the need to clarify and reformulate public policies relating to the handicapped. The Committee Report stated:

> Too often we automatically make the assumption that nothing can be done. With that assumption made, even the best programming and the most advanced services cannot meet their goals. *It is against the basic tenets of the scientific process to make an assumption of no hope and no help. No less should be true of public policy. In the case of individuals with handicaps, mak-*

> *ing this assumption all too often has resulted in the violation of their basic rights as human beings*, and has condemned them to live useless lives. *Foresight and a strong commitment to the worth and dignity of the human life could have allowed them to live their lives with respect and dignity as first class citizens.*

Id. at 6400-6401 (emphasis supplied).

The Committee also directed the Conference:

> . . . to address itself directly to the problem posed by the denial of the basic rights of individuals with handicaps. In examining this area, the Committee expects that the Conference will identify those areas where civil rights have been denied and will make explicit recommendations for change.

Id. at 6406-6407. It further recognized the need for diagnosis, evaluation and treatment of handicaps early in a child's life.

> *Diagnosis, evaluation, and treatment early in a child's life could enable many children with handicaps to blunt the effects of these disabilities.* The Committee urges local governments, States, and the White House Conference to review and explore *new mechanisms to insure that these important early life measures are provided for all children.*

Id.

Far from a concern limited to "access" issues, the Congress was urging and embarking upon a broad attack on *all* barriers to the handicapped, *including health service and medical treatment decisions*. Moreover, it expressly affirmed providing treatment to *all handicapped children* early in life. It is, therefore, a glaring

misstatement and a denial of the Congressional will to say that "the legislative history . . . focuses on discrimination against *adults and older children* and denial of access to federal programs." *United States* v. *University Hospital, State University of New York*, 729 F. 2d at 158, *citing American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. at 401 (emphasis supplied).

In truth, the 1974 amendments greatly expanded the reach of Federal law to protect all handicapped persons from all kinds of discrimination. At the same time, Congress was urging a new sensitivity and commitment to the needs and problems of the handicapped, as well as examination and revision of public policy dealing with such problems. It was thus wholly consistent with the legislative intent for then Secretary of Health, Education and Welfare Joseph Califano to declare in a communication to the Congress that a "new era of civil rights in America" had begun with the 1974 amendments. *See* Hearings Before the Subcommittee on Select Education of the Committee on Education and Labor of the House of Representatives, 95th Cong. 1st Sess. 76. In short, as this Court stated recently:

> [The] 1974 Amendments to the Act clarified the scope of Section 504 by *making clear that those charged with administering the Act had substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination.*

Alexander v. *Choate*,_U.S._(January 9, 1985), Slip Op. at 16, n. 24 (emphasis supplied).

The 1978 Amendments. In 1977, Congress held hearings on the implementation of Section 504 and enacted amendments in 1978. The amendments made Section 504

applicable to the Executive Branch and the U.S. Postal Service and provided for regulations necessary to implement other provisions of the 1978 amendments. In discussing the conference report on the 1978 amendments, Representative Jeffords stated:

> Finally, under section 504 . . . . the conference accepted a provision which I authored which I think brings fairness and equity to the entire picture in eliminating discrimination against the handicapped wherever it exists. In September 1977, the Justice Department issued an opinion at the request of the Department of Health, Education, and Welfare, declaring that the Federal Government was exempt from section 504. Somehow it did not seem right to me that the Federal Government should require States and localities to eliminate discrimination against the handicapped wherever it exists and remain exempt themselves. So I developed a provision which is in this conference report that extends coverage of section 504 to include any function or activity in every department or agency of the Federal Government.

124 Cong. Rec. 38551 (October 14, 1978).

The amendments also enhanced remedial powers for violations of Section 504. 29 U.S.C. Section 794a was enacted to provide as follows:

> The remedies, procedures, and rights set forth in title VI of the Civil Rights Act of 1964, [42 U.S.C. Section 2000d et seq.] shall be available to any person aggrieved by any act or failure to act by any recipient of Federal assistance or Federal provider of such assistance under section 794 of this title.

An additional provision of the 1978 amendments made an award of attorney's fees available to prevailing parties in actions brought to enforce Section 504. Thus, Congress once again incorporated by reference the broad provisions of the Title VI of the Civil Rights Act of 1964 to expand the remedies available to enforce Section 504. *Cf. United States* v. *Weber*,_U.S._(March 20, 1984), Slip Op. at 10.

C. The Congressional Analogy to Section 601 of the Civil Rights Act of 1964.

Because the Congress specifically intended that the reach and scope of Section 504 be identical to Section 601 of the Civil Rights Act of 1964 (now 42 U.S.C. 2000d), it is useful to review briefly the scope of that section. Section 601 bans discrimination on the ground of race, color or national origin in any program or activity receiving Federal financial assistance. The regulations promulgated thereunder, like the regulations in this case, provide, among other things, that Federal aid recipients may not:

> (i) provide any service, financial aid, or other benefit to an individual which is different, or is provided in a different manner, from that provided to others under the program;
>
> (ii) restrict an individual in any way in the enjoyment of any advantage or privilege enjoyed by others receiving any service, financial aid, or other benefit under the program; or
>
> (iii) discriminate in the availability or use of any academic . . . or other facilities of the grantee or other recipient.

40 C.F.R. Section 80.3(b)(1) and 80.5(b).

In *Lau* v. *Nichols*, 414 U.S. 563 (1974), this Court

interpreted Section 601 and the regulations described above to require the San Francisco school system to provide English language instruction to 1,800 non-English speaking Chinese students on grounds that *the failure to provide such instruction* denied them a meaningful opportunity to participate in the public educational program based solely on their race. Moreover, in *University of California Regents* v. *Bakke*, 438 U.S. 265 (1977), each of the three opinions of the Court acknowledged that the purpose of Section 601 was to provide the Executive Branch with the authority and the obligation to terminate financial support to any private or governmental activity which discriminated on the basis of race. *See id.* at 285, 336 and 413. Thus, both the regulations promulgated under Section 601 and the application of Section 601 to discrimination against individuals and groups, including the failure to provide equal opportunity under governmental programs, are far reaching and reflect an uncompromising policy to eradicate racial discrimination under any Federal program or activity.

The significance of the Congressional analogy to Section 601 was eloquently expressed by Judge Winter in dissent in the *University Hospital* case:

> The government has never taken the position that it is entitled to override a medical judgment. Its position rather is that it is entitled under Section 504 to inquire whether a judgment in question is a *bona fide* medical judgment. While the majority professes uncertainty as to what this means, application of the analogy to race (as in Section 601 cases) eliminates all doubt. A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life-threatening digestive problem be-

> cause an infant has Down's Syndrome is not a *bona fide* medical judgment.

729 F.2d at 162. That Section 601 of the Civil Rights Act of 1964 would reach this far is absolutely clear from its legislative history. Its principal sponsor in the House, Representative Emmanuel Celler, stated:

> The bill would offer assurance that hospitals financed by Federal money *would not deny adequate care to Negroes* . . . . It would, in short, assure the existing right to equal treatment in the enjoyment of Federal funds.

110 Cong. Rec. 1519 (January 31, 1964) (emphasis supplied).

In other words, Section 601 is a broad mandate against discrimination on account of race in connection with any Federal program. It has been construed liberally, as the Congress intended. Section 504, should likewise be given a broad reach and scope, as the Congress intended. *Alexander* v. *Choate*_U.S._(January 9, 1985), Slip Op. at 16, n. 24.

D. The Congressional Analogy to Section 901 of the Education Amendments of 1972.

The Congress also analogized Section 504 to Section 901 of the Education Amendments of 1972, now 20 U.S.C. 1681. Section 901 provides:

> No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance, except that [specified exceptions omitted] . . . .

In *Cannon* v. *University of Chicago*, 441 U.S. 677 (1979),

this Court identified the primary congressional purpose behind Section 901 to be "to avoid the use of federal resources to support discriminatory practices." *Id.* at 704. It also stated that this purpose "is general'y served by the statutory procedure for the termination of federal financial support for institutions engaged in discriminatory practices." *Id.* Likewise, in *North Haven Board of Education* v. *Bell* 456 U.S. 512, 521 (1982), this Court "recognized the need to accord [Title IX] a sweep as broad as its language." *Grove City College* v. *Bell*,_ U.S._(February 28, 1984), Slip Op. at 8. In *Grove City*, this Court also made clear that:

> Title IX was patterned after Title VI of the Civil Rights Act of 1964. The drafters of Title VI envisioned that the receipt of student aid funds would trigger coverage, and, *since they approved identical language, we discern no reason to believe that the Congressmen who voted for Title IX intended a different result* [citations omitted].

Id. at 10. It is difficult to discern how Section 504 of the Rehabilitation Act, which Congress intended as a broad weapon against discrimination based on handicap, should not be given the same expansive coverage as Section 901 which Congress viewed as a far reaching weapon against sex discrimination in education.

CONCLUSION

In its response to the Department of Health and Human Service's proposed rules that are the subject of this case, the American Medical Association argued, in part, that deference should be made to parental judgment in the treatment of seriously deformed newborns:

> The presumption is that the love which parents usually have for their children will be dominant

> in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

49 F.R. No. 8 at 1629 (January 12, 1984). While these assumptions and conclusions are basically sound, we cannot readily assume, as a matter of social policy, that every parent will act unselfishly or will be able to withstand the new and severe emotional pressures of being the parent of a handicapped newborn infant. Likewise, not all physicians or medical professionals will advise that ordinary medical treatment be provided for such infants. In such instances, it is not inappropriate or unreasonable for the Department to establish minimally intrusive protective and investigational measures and to require that "the long-standing requirements and mechanisms of state law for defining the limits of parental authority not be rendered, through discriminatory actions of recipient hospitals, *de facto* inoperative." *Id.* at 1631.

Surely, it would be a perversion of the Congressional intent for the protection afforded by Section 504 to be withheld from handicapped newborn infants. The statutory language is broad and far reaching and without exception. The legislative history likewise evinces a strong intent for broad application to all handicapped individuals, in a manner consistent with Section 601 of the Civil Rights Act of 1964 and Section 901 of the Education Amendments of 1972. Furthermore, there is no indication that the Congress intended that the full protection of Section 504 stop upon admission to the hospital or apply only at some indeterminate time after

birth. In the absence of Congressional expression to the contrary, the courts should give Section 504 its intended broad effect.

Justice Douglas quite properly stated that "when the Court used substantive due process to determine the wisdom or reasonableness of legislation, it was indeed transforming itself into the Council of Revision which was rejected by the Constitutional Convention." *Flast* v. *Cohen*, 392 U.S. 83, 107 (1968); *cf. Saia* v. *New York*, 334 U.S. 558, 571 (1948) (Jackson, J. dissenting) ("But I did not suppose our function was that of a council of revision."). Unfortunately, in this case, the lower courts have disregarded the clear Congressional intent for broad and unrestricted application of Section 504. Not unlike a Council of Revision, they have transgressed the express legislative will and substituted their own social policy views. This mistake in judgment by the lower courts should not be permitted to stand in tne place of otherwise valid legislation.

"[The] only check upon our own exercise of power," Justice Stone once wrote concerning this Court, "is our own sense of self-restraint." *United States* v. *Butler*, 297 U.S. 1, 79 (1936). It is appropriate that self-restraint be exercised in this case by reversal of the lower court decision.

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In the

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OCTOBER TERM, 1985

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INTEREST OF THE AMICI

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SUMMARY OF ARGUMENT

The Secretary of Health and Human Services, pursuant to the broad authority delegated to her by Congress under § 504 of the Rehabilitation Act of 1973, has promulgated regulations to prohibit the denial of beneficial medical treatment to handicapped newborns by hospitals receiving federal financial assistance. The court of appeals held that these regulations, because they affect medical decision-making, do not fall within the purview of § 504. This result contradicts the plain language of § 504, ignores relevant legislative and regulatory history, distorts the reality of the medical problems faced by handicapped infants, and frustrates the clear will of Congress to eliminate discrimination in federally funded programs.

Contrary to the court's holding, a handicapped infant can be "otherwise qualified" to receive medical services for purposes of § 504. In most cases, it can be clearly determined whether a particular infant will benefit from treatment and whether a denial of treatment would discriminate solely on the basis of handicap. Since hospitals commonly seek court approval for treatment upon infants, these regulations do not require "affirmative action."

The legislative history establishes that § 504 is a broad, remedial provision, and that there is no legislative intent contrary to these regulations. Discrimination against handicapped infants was not a public issue in 1973, although it is a contemporary form of the evils against which § 504 is directed. Moreover, in amendments to the Rehabilitation Act passed in

1978, Congress provided for the care and treatment of the same handicapped infants covered by these regulations.

In striking down these regulations, the court failed to give due deference to an agency charged with the administration of a statute. The Department of Health and Human Services and its predecessor agency have consistently applied § 504 to prohibit discrimination by health care providers, and to ensure appropriate levels of medical services to all handicapped individuals. Hence, HHS' efforts to bring § 504 to bear on instances of discrimination against handicapped infants ought to be given great deference, and upheld.

I.
INTRODUCTION

Section 504 of the Rehabilitation Act of 1973[1] enacts a simple yet powerful principle into federal law: federal funds may not be used to promote discrimination by a recipient of federal assistance against an "otherwise qualified handicapped individual."[2] Congress has directed the Secretary of the Depart-

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[1] No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulations may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

29 U.S.C. § 794 (1982).

[2] Section 706(7) defines "handicapped individual":

(7)(A) Except as otherwise provided in subparagraph (B), the term "handicapped individual" means any individual

(footnote continued on next page)

ment of Health and Human Services (HHS) to promulgate regulations to carry out the broad, remedial purposes of § 504. S.Rep. 93-1297, 93d Cong. 1st Sess.39-40, *reprinted in* [1974] U.S. Code Cong. & Adm. News 6373, 6390-91. This Court has recognized that "those charged with administering [§ 504] [have] substantial leeway to explore areas in which discrimination against the handicapped pose[s] particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander* v. *Choate*, 105 S.Ct. 712, 722-23 n.24 (1985).

Acting under this authority, the Secretary promulgated regulations applying § 504 to discriminatory medical treatment decisions involving handicapped infants. The regulations state that health care providers receiving federal financial assistance may not withhold treatment or nourishment "solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite

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(footnote continued from preceding page)

> who (i) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (ii) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to subchapters I and III of this chapter.
>
> (B) Subject to the second sentence of this subparagraph, the term "handicapped individual" means, for purposes of subchapters IV and V of this chapter, any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment. For purposes of sections 793 and 794 of this title as such sections relate to employment, such term does not include any individual who is an alcoholic or drug abuser whose current use of alcohol or drugs prevents such individual from performing the duties of the job in question or whose employment, by reason of such current alcohol or drug abuse, would constitute a direct threat to property or the safety of others.

29 U.S.C. § 706(7) (1982).

of such impairments, will benefit medically from the treatment or nourishment." 45 C.F.R. § 84.55(f)(1) (1984).

The court of appeals held these regulations invalid, reasoning that Congress never intended for § 504 to apply to treatment decisions involving handicapped infants. In so holding, the court unduly restricted the broad, remedial scope of § 504. The court failed to take into account the plain language of § 504, the expressed intent of Congress to ensure adequate medical services for handicapped infants, the delegation of broad authority to HEW, and the consistent regulatory history under § 504. When these factors are properly considered, it is clear that the court's holding was in error and should be reversed.[3]

II.

A PROHIBITION OF DISCRIMINATION IN THE DENIAL OF MEDICALLY INDICATED, BENEFICIAL TREATMENT TO HANDICAPPED INFANTS IS WARRANTED BY THE PLAIN STATUTORY LANGUAGE OF § 504

A. The Court of Appeals Ignored Fundamental Principles of Statutory Construction in Restricting the Scope of § 504

In determining the scope of § 504, the proper starting point is the language of the statute. *Landreth Timber Co.* v. *Landreth*, 105 S.Ct. 2297, 2301 (1985); *North Haven Board of Education* v. *Bell*, 456 U.S. 512, 520 (1982). In the absence of a clearly expressed, contrary legislative intent, the plain language of § 504 controls its construction. *North Dakota* v. *United States*, 103 S.Ct. 1095, 1102-03 (1983); *Jefferson County Pharmaceutical Ass'n, Inc.* v. *Abbott Laboratories*, 103 S.Ct. 1011, 1016 (1983).

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[3] The court of appeals did not publish its opinion, but based its decision on *United States* v. *University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984). *American Hospital Association* v. *Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984). Accordingly, in this brief, references to the court's opinion are references to the opinion in *University Hospital*.

As a remedial statute, § 504 must be broadly construed in order to effectuate its purposes. *Sedima, S.P.R.L.* v. *Imrex Co.*, 105 S.Ct. 3275, 3286 (1985); *Consolidated Rail Corp.* v. *Darrone*, 104 S.Ct. 1248, 1255 (1984). As long as these regulations are reasonably related to the purpose of the enabling legislation—to protect handicapped persons from discrimination and the denial of benefits in federally assisted programs—they must be sustained. *Lau* v. *Nichols*, 414 U.S. 563, 571 (1974) (Stewart J., concurring); *Mourning* v. *Family Publications Services, Inc.*, 411 U.S. 356, 369 (1973); *Thorpe* v. *Housing Authority of the City of Durham*, 393 U.S. 268, 280-81 (1969).

Disregarding these fundamental principles of statutory construction, the court of appeals constricted the plain language of § 504, both in the scope of handicapped individuals protected and in the type of programs covered. The court failed to give priority to the plain statutory language of § 504. Rather, the court limited the scope of the plain language by its interpretation of the regulatory history, concluding that the regulations at issue are "flatly at odds" with the "limited view" of the scope of § 504 allegedly taken by the Department of Health, Education and Welfare (HEW). 729 F.2d. at 154. As demonstrated in Sec. IV of this brief, the court misread the regulatory history; an accurate reading establishes that HEW and HHS have consistently expressed a broad view of the scope of § 504. By giving this erroneous reading of the regulatory history priority over the plain statutory language, the court failed to adhere to the principle that the plain language controls unless contradicted by a clearly expressed, contrary legislative intent. *North Haven*, 456 U.S. at 522.

B. A Handicapped Infant Can Be An "Otherwise Qualified Handicapped Individual" And A Denial of Medically Indicated Treatment Is A Denial of Benefits Contrary to § 504

By its plain language, § 504 prohibits discrimination, the exclusion of participation, and the denial of benefits solely by reason of handicap, against any "otherwise qualified handicapped individual" in federally assisted programs. The court of appeals held that the regulations at issue are invalid because

a handicapped infant in need of medical treatment is not "otherwise qualified" for purposes of § 504 and because medical treatment is not an activity covered by § 504. The court reasoned that the "otherwise qualified" criterion only applies to "static" programs such as employment, education and transportation, and not to "fluid" programs such as medical treatment. Relying on *Doe* v. *New York University*, 666 F.2d 761 (2d Cir. 1981), the court added that the "otherwise qualified" criterion applies "only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question;" since a handicapped infant's need for medical services often arises from the handicapping condition, such infants cannot be "otherwise qualified." 729 F.2d at 156. Finally, the court reasoned that since handicaps are often related to the medical condition it will "rarely, if ever, be possible to say that a particular decision [not to provide medical treatment] was discriminatory." *Id.* at 156-57. Thus, according to the court, the "fluidity" of medical decisionmaking, and the relationship between the infant's handicap and need for medical services, create such uncertainty regarding both qualification and discrimination that no case can fall within the scope of § 504.

In so holding, the court failed to properly apply the plain statutory language, and disregarded compelling evidence contrary to its own factual assumptions. The distinction between "static" and "fluid" programs is a creation of the court of appeals, not of Congress, and has no foundation in the plain language or the legislative history. *Cf. Chevron, U.S.A., Inc.* v. *Natural Resources Defense Council*, 104 S.Ct. 2778, 2792 (1984). Similarly, there is no factual basis for the sweeping assumption that all medical treatment decisions for handicapped infants are so fluid and uncertain that it is impossible to determine that a particular infant is qualified for medical service or is being discriminated against in the denial of such services. Because the court assumed that the handicap and "the services" are always inextricably intertwined, it failed to distinguish between an untreatable handicap and a treatable medical condition for which an infant can be qualified.

Contrary to the court's holding, handicapped infants do meet the criteria for "otherwise qualified handicapped individual." This Court has stated that "[a]n otherwise qualified person is one who is able to meet all of a program's requirements in spite of his handicap." *Southeastern Community College* v. *Davis*, 442 U.S. 397, 406 (1979). "[A] person who suffers from a limiting physical or mental impairment still may possess other abilities that permit him to meet the requirements of various programs." *Id.* at n.6. Moreover, "the question of who is 'otherwise qualified' and what actions constitute 'discrimination' under the Section would seem to be two sides of a single coin; the ultimate question is the extent to which a grantee is required to make reasonable modifications in its program for the needs of the handicapped." *Alexander*, 105 S.Ct. at 720 n.19.

Based on these elements, handicapped newborns who require medical treatment can be "otherwise qualified." The Secretary has properly applied this criterion to the context of handicapped infants. As the Secretary stated in her brief below, "[i]n the context of a health care program, there are no qualifications other than the ability, despite handicap(s), to benefit from medical treatment. If a child's handicapping condition does not prevent him from benefitting from surgery to correct other problems, he must be considered 'otherwise qualified.'" Brief for the Defendant-Appellant Margaret Heckler 19, *American Hospital Association* v. *Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984).[4] *See also*, 49 Fed.Reg. 1636 (1984) (to be codified at 45 C.F.R. Pt. 84).[5]

That a handicapped infant can be "otherwise qualified" is demonstrated by the report of the President's Commission for

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[4] Respondents contend that § 504 does not encompass children. Based on the plain language of § 504, however, "individual" must be taken to encompass persons "of all ages." *Smith* v. *Robinson*, 104 S.Ct. 3457, 3472 (1984).

[5] From the beginning, HHS regulations have broadly defined "qualified" in a manner that encompasses handicapped newborns.

(k) 'Qualified handicapped person' means:. . .

(footnote continued on next page)

the Study of Ethical Problems in Medicine. The Commission's analysis of the issue divides infant treatment cases into three categories: (1) where treatment is available "that would clearly benefit the infant," (2) where "all treatment is expected to be futile," (3) where "the probable benefits to an infant from different choices are quite uncertain."[6] Although the court of appeals assumed that no clear distinctions can ever be made in the medical treatment of handicapped infants, so as to allow the conclusion that certain decisions may be discriminatory, 729 F.2d at 157, the Commission concluded that "the three situations need to be considered separately, since they demand differing responses." President's Commission at 217. The Commission acknowledged that surgery may leave such infants with permanent handicaps and that "the expectation of such handicaps" is often considered in deciding whether to treat. However, the Commission concluded "that a very restrictive standard is appropriate: such permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued treatment would not be a net benefit to the infant." *Id.* at 218.[7]

The Commission's report demonstrates that it *is* possible to know with certainty whether treatment will be "beneficial"

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> (4) With respect to *other services*, a handicapped person who meets the essential eligibility requirements for the receipt of such services.

45 C.F.R. § 84.3(k)(4) (1977) (emphasis added).

[6] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 217 (1983) [President's Commission].

[7] The "benefit" is to be viewed "from the infant's own perspective," and excludes "consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society." President's Commission at 219. The Commission specifically stated that "the handicaps of Down Syndrome . . . do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract." *Id.*

and, thus, whether nontreatment would be discriminatory.[8] Indeed, the Commission acknowledged that "most" cases will fall into the "clearly beneficial" or "futile" categories, and only a "smaller number" will raise hard questions of uncertainty. *Id.* at 218, 220.

Therefore, the court erred in holding that the relationship between the handicapping condition and the services in question makes § 504 inapplicable to any case involving medical treatment of handicapped infants. 729 F.2d at 156-57. The court failed to recognize that an infant's need for medical services may be totally unrelated to the handicapping condition. The court also failed to distinguish between an untreatable handicap, and a related, but separate, medical condition which is treatable.[9] In one case, there is no relation between the handicap and the service; in the second, the relationship in no way mitigates the infant's ability to benefit from the service.[10] In both cases, the infants are "otherwise qualified" to receive

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[8] In this regard, the U.S. Commission on Civil Rights has noted that "[w]hile occasional denials of routine medical care have been reported, a much more serious problem involves the apparent withholding of lifesaving medical treatment for individuals, frequently infants, solely because they are handicapped." U.S. Com. on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 35-36 (Sept. 1983). *See also, In re the Treatment and Care of Infant Doe*, No. GU 8204-004A (Monroe Co.Ind.Cir.Ct., Mem.Op., Apr. 12, 1982), *writ of mandamus dismissed sub nom. State ex rel. Infant Doe* v. *Baker*, No. 482 S 140 (Ind.Sup.Ct. May 27, 1982), *cert. denied, Doe* v. *Bloomington Hospital*, 104 S.Ct. 394 (1983).

[9] Respondents obscure this distinction by claiming that the Government itself does not apply § 504 when "a certain level of defect" is reached. Respondents' Brief In Opposition To Petition For Writ Of Certiorari at 29. But the "defect" which renders § 504 inapplicable is a medical one that renders medical treatment not "beneficial" within the plain language of § 504, not one that is untreated for nonmedical reasons.

[10] For example, infants with Down Syndrome are sometimes afflicted with an esophageal atresia. Although the Down Syndrome cannot be reversed, the atresia can be surgically corrected, and the infant is thus "otherwise qualified" to receive the surgery.

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medical treatment, and a failure to provide appropriate treatment is forbidden by the plain language of § 504.

Accordingly, the court of appeals erred when it held that handicapped infants are not "otherwise qualified' to receive medical treatment and that the failure to provide such treatment is not discriminatory. The failure to provide beneficial medical treatment to an infant solely because of a handicap or the expectation of future handicap meets every element of § 504, is reasonably related to the purposes of § 504, and is a proper subject for regulation under that section.

C. The Regulations Require Equal Treatment, Not Affirmative Action, In the Medical Care of Handicapped Infants

Respondents additionally contend that these regulations are unauthorized under *Southeastern Community College* v. *Davis*, 442 U.S. 397 (1979), because they mandate "affirmative action" by requiring health care providers to seek court review of parental refusal for treatment. In *Davis*, this Court held that "substantial" modification of an institution's programs amounts to affirmative action; unless there is "substantial" modification or "fundamental alteration," no affirmative action is involved. *Id.* at 411-12, *Alexander*, 105 S.Ct. at 721 n.20.

No modification, much less a substantial one, is required by these regulations. The regulations do not specifically require providers to treat infants in violation of parental consent or to seek judicial review. But hospitals in many cases already seek court orders to overrule parental refusal for medical treatment. If a hospital would ordinarily seek a state court order in the face of parental objection to administer medically indicated treatment to a nonhandicapped infant, to not seek such an order in the case of a

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See Brief Amicus Curiae of American Association on Mental Deficiency, et al.

handicapped infant, because the infant is handicapped, and to hide behind "parental responsibility," is to discriminate.[11]

Historically, physicians, hospitals, and state agencies have gone to court where parents refused medical treatment for nonhandicapped children.[12] Courts have ordered treatment for minors in numerous life-threatening situations.[13] In cases where there was no immediate threat to a child's life, some courts have ordered treatment,[14] while others have refused to order treatment, mainly because the proposed

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[11] This disposes of the District Court's objection that "University Hospital has failed to perform the surgical procedures in question, not because Baby Jane Doe is handicapped, but because her parents have refused to consent to such procedures." *University Hospital*, 575 F.Supp. at 614. This erroneously assumes that the hospital's obligation ends with the parent's refusal. If the hospital would seek to override the parental refusal of a Jehovah's Witness to allow a blood transfusion for his child, the hospital must also seek an override for medically indicated treatment for a handicapped infant. Parents have the ultimate responsibility *until* they neglect that responsibility. *Wisconsin* v. *Yoder*, 406 U.S. 205, 232 (1972), *Prince* v. *Massachusetts*, 321 U.S. 158, 166-67 (1944).

[12] For example, Jehovah's Witnesses cannot refuse a transfusion for a child, if such is needed to avoid substantial harm to the child. *Jehovah's Witnesses* v. *King Co. Hosp.* 278 F.Supp. 488 (W.D.Wash. 1967), *aff'd per curiam*, 390 U.S. 598 (1968), *Application of President and Directors of Georgetown College*, 331 F.2d 1000 (D.C.Cir.), *reh. en banc denied*, 331 F.2d 1010, *cert. denied*, 377 U.S. 978 (1964).

[13] *Matter of Hamilton*, 657 S.W.2d 425 (Tenn.App. 1983) (12-year-old girl with Ewing's sarcoma), *People In interest of D.L.E.*, 645 P.2d 271 (Colo. 1982) (14 year old with gran mal epileptic condition), *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978) (*Green I*), 393 N.E.2d 836 (1979) (*Green II*) (leukemia).

[14] *In Re Adam*, 9 Fam.L.Rep. 2121 (D.C.Super.Ct.Fam.Div. Nov. 22, 1982), *Matter of Jensen*, 54 Or.App. 1, 633 P.2d 1302 (1981) (hydrocephalus), *Matter of Gregory S.*, 85 Misc.2d 846, 380 N.Y.S.2d 620 (1976).

treatment would not necessarily cure the medical condition.[15] This is merely consistent with deference to reasonable medical decisionmaking.

Courts have also ordered treatment for handicapped children.[16] Whether courts have or have not ordered treatment for handicapped persons, they have held that the intelligence or mental capacity of the individual is irrelevant.[17]

The regulations at issue are entirely consistent with this body of law. Since health care providers commonly seek judicial review, it cannot seriously be asserted that § 504 will "spawn" such litigation, 729 F.2d at 157, or that seeking court intervention is "affirmative action," since no "substantial" modification will be required in what health care providers have an independent duty to do. The "burden" of nondiscrimination does not constitute affirmative action.

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[15] *In re CFB*, 497 S.W.2d 831 (Mo.App. 1973) (psychiatric care), *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972), *after remand*, 452 Pa. 373, 307 A.2d 279 (1973).

[16] *Commissioner of Social Services* v. *Catherine and Phillip Guatrone*, No. N-2029 (Fam.Ct. of N.Y., Bronx, May 31, 1984) (Down Syndrome), *In re Phillip B.*, 92 Cal.App.3d 796, 156 Cal.Rptr. 48, *cert. denied, Bothman* v. *Warren, B.*, 445 U.S. 949 (1979), *Guardianship of Phillip B.*, 139 Cal.App.3d 407, 188 Cal. Rptr. 781 (1983), *Application of Cicero*, 101 Misc.2d 699, 421 N.Y.S.2d 965 (N.Y.Sup.Ct. 1979), *In Re McNulty*, No. 9190 (Probate Ct. Essex Co., Mass. Feb. 15, 1978), *Maine Medical Center* v. *Houle*, No. 74-145 (Super.Ct. Cumberland Co., Me. Feb. 14, 1974) (treatment ordered for multiple defects and blocked esophagus), *Muhlenberg Hosp.* v. *Patterson*, 128 N.J.Super. 498, 320 A.2d 518 (1974), *In re Teague*, No. 104-212-81886 (Cir.Ct. Baltimore, Md., filed Dec. 4, 1974) (spina bifida).

[17] *See, e.g., Superintendent of Belchertown State School* v. *Saikewicz*, 373 Mass. 728, 370 N.E.2d 417, 431 (1977) ("[T]he value of life under the law (has) no relation to intelligence or social position."). *See also, Maine Med. Center* v. *Houle*, No. 74-145 (Super.Ct. Cumberland Co. Me. Feb. 14, 1974). "[T]here is no legal precedent" for the judgment that the quality of life affects its value. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 Stan.L.Rev. 213, 237, 242 (1975).

The plain language of § 504 prohibits the failure to provide, solely by reason of handicap, medically-indicated treatment to handicapped infants who can benefit from such treatment. This plain language controls unless a clearly expressed, contrary legislative intent exists.

III.

THE LEGISLATIVE HISTORY COMPELS A BROAD APPLICATION OF § 504 TO PROSCRIBE THE DISCRIMINATORY TREATMENT OF HANDICAPPED INFANTS.

A. The Legislative History Establishes That § 504 Is A Broad, Remedial Provision.

The legislative history of § 504 is nearly silent on the narrow question of providing medical treatment to handicapped infants. Nevertheless, the Rehabilitation Act, as enacted and amended, provides a wide range of research and services for the handicapped, with a priority for "severely handicapped" persons, including infants. Section 504, in turn, was intended to establish a comprehensive, federal policy prohibiting discrimination in *all* federally-assisted programs.[18] Both indicate that handicapped infants are among the persons covered by these laws.

The legislative proposals which became § 504 were jointly introduced in the House and Senate, separate from the Rehabilitation Act, in late 1971 and early 1972. Upon introducing H.R. 12154[19] in December 1971, Rep. Vanik referred to the growing number of handicapped individuals in the United States, including the yearly birth of 100,000 babies with "defects." In introducing S.3044 in January

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[18] *See generally*, R. Scotch, *From Good Will to Civil Rights* (1984).

[19] Entitled "A bill to amend the Civil Rights Act of 1964 in order to prohibit discrimination on the basis of physical or mental handicap in federally assisted programs." 117 Cong.Rec. 45974-75 (1971).

1972,[20] Senator Humphrey "focused [his] attention on the handicapped child," and referred to the variety of handicapped individuals including "the 100,000 babies born with defects each year." 118 Cong.Rec. 525-526 (1972). He stated that "[e]very child—gifted, normal, and handicapped—has a fundamental right to educational opportunity and the right to health." *Id.*[21]

In September, 1972, Senator Randolph, Chairman of the Senate Subcommittee on the Handicapped, introduced S. 3987, entitled the "Rehabilitation Act of 1972." *Id.* at 30680. The bill was introduced to replace the 50 year old Vocational Rehabilitation Act, the Smith-Fenn Act of 1920. *Id.* at

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[20] Entitled "A bill to amend the Civil Rights Act of 1964 in order to prohibit discrimination on the basis of physical or mental handicap in federally assisted programs."

[21] These statements by Vanik and Humphrey indicate that handicapped infants are among the persons covered by these bills. *See also* 118 Cong.Rec. 14244 (Statement of Rehabilitation Services Administration (RSA) Commissioner Edward Newman, including reference to infants with birth defects). Sen. Randolph noted:

> Of whom do we speak when we speak of the severely handicapped? . . . Do we have many such people, or are they few in number? . . . We all know of the progress that has been in the medical profession. We know of the improvements which have been made from the standpoint of prenatal and postnatal care, resulting in higher rates of survival among our multiple handicapped infants. The changing concept of the right to treatment, the advent of new drugs and new surgical techniques, permits lives previously lost to be saved. But patients are often left with physical or mental handicaps.
>
> Once we thought the lives of such people were a loss, that we could not return them to active levels of society where they would be productive citizens. Now, however, we know that that can be done. We know it has been done.

119 Cong.Rec. 10802. *See also* n.23 *infra*.

32279, 32304-305. A section 604, prohibiting "any kind of discrimination against handicapped individuals with respect to any program receiving Federal financial assistance," was included in Title VI of S. 3987. *Id.* at 30681, 32265, 37302.

President Nixon vetoed the corresponding House Bill, H.R. 8395, in October, 1972. The bill was reintroduced in the Senate as S. 7 in January, 1973, which was approved by the Senate in February, 1973, with the nondiscrimination provision included as § 705. 119 Cong.Rec. 5900-901, 5915 (1973). President Nixon vetoed S. 7 on March 27, 1973.[22]

The Rehabilitation Act was introduced for a third time in May, 1973. The House Bill, H.R. 8070, including the nondiscrimination provision, § 503, passed the House in June, 1973.[23] 119 Cong.Reg. 18127-28.

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[22] Appellees contend that the Presidential vetoes of 1972 and 1973, and the Congressional deletion of various programs, indicate an intention that the Act not include any "medical" programs. But those presidential vetoes were based on cost, duplication, and categorization of types of services, not on any concern with federal oversight of medical decisionmaking. 118 Cong.Rec. 3723, 119 Cong.Rec. 9597, 24570. In addition, the veto memoranda never referred to the nondiscrimination section.

[23] Immediately before the vote on the bill, Rep. Vanik noted that H.R. 8070 incorporated his original provision against discrimination. He stated that H.R. 8070 was just a small beginning and urged Congress to move ahead to provide more programs for the education of handicapped children. He suggested that HEW has "impounded funds, that were designated to help handicapped children." He condemned the practice of ancient Greece where "the people would take the handicapped newborn and leave them to die of exposure on the mountainside," asking whether "we are guilty of the same type of gross neglect in this country!" 119 Cong.Rec. 18137.

The Senate debated the new Senate bill S. 1875 in July, 1973. 119 Cong.Rec. 24550.[24] The prohibition on discrimination was included in its final form as § 504. *Id.* at 24562. President Nixon signed the Rehabilitation Act of 1973, P.L. 93-112, into law on September 26, 1973.[25]

Throughout the debates of the 92nd, 93rd, and 94th Congresses, the precise meaning of § 504, with exception for the statements of Rep. Vanik and Senator Humphrey, was almost never explained. Section 504 "was not discussed in any of the hearings held prior to the law's passage . . ."[26] Its language was described or quoted numerous times, without exception, in a very straightforward and absolute manner.[27]

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[24] On the same day that the Senate considered the Rehabilitation Act of 1973, July 18, 1973, S.J. Resolution 118 was proposed to establish a White House Conference on the Handicapped. 119 Cong.Rec. 24442. The joint resolution proposed that the federal government work with the states to develop programs that would, among other things, "provide[] educational, health and diagnostic services for all children early in life so that handicapped conditions may be discovered and treated early." S.J.Res. 18 was passed by the Senate on July 18, 1973 and incorporated into Title III of the Rehabilitation Act Amendments of 1974. 120 Cong.Rec. 30536, 34722 (1974).

[25] Throughout the debates on the House and Senate Bills which eventually formed the Rehabilitation Act of 1973, Rep. Vanik and Senator Humphrey emphasized repeatedly that the nondiscrimination sections in these bills incorporated the intent of their original bills to amend the Civil Rights Act of 1964. 118 Cong.Rec. 32310, 119 Cong.Rec. 635, 6144-45, 7114, 18137. The remarks "of the sponsor of the language ultimately enacted are an authoritative guide to the statute's construction" and should be accorded "substantial weight." *North Haven*, 456 U.S. at 526.

[26] Scotch, *supra* n.19, at 4.

[27] *See* 117 Cong.Rec. 45945 (1971); 118 Cong.Rec. 525, 526, 8399, 8894, 11797, 16371, 30681, 30682, 30683, 32280, 32281, 32282, 32294, 37302, 32310, 35155, 35163, 35837 (1972); 119 Cong.Rec.

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Nevertheless, Senator Cranston, Acting Chairman of the Senate Subcommittee on the Handicapped, said that § 504 was intended to deal "comprehensively" with discrimination. 119 Cong.Rec. 5862, 24569 (1973). This Court has noted that § 504 was consciously patterned after the broad provisions of Title VI of the Civil Rights Act of 1964. 42 U.S.C. § 2000(d) (1982), *Alexander*, 105 S.Ct. at 718 n.13, *Darrone*, 104 S.Ct. at 1254 n.13.

In hindsight, it is apparent that Congress had no reason to specifically consider the medical treatment of handicapped infants in 1973: it simply was not a prominant social issue. The first medical article openly discussing the subject was published after the 1973 Act was signed into law. Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 N.Eng.J.Med. 890 (Oct. 25, 1973).[28] Duff and Campbell lifted the veil on "the public and professional silence on a major social taboo." *Id.* at 894. Congress' first hearings on the subject in 1974 were themselves "prompted" by the article. "Panel Told Defective Infants Are Allowed To Die," New York Times, June 12, 1974, at 18, col. 3, *Medical Ethics: The Right to Survival, 1974: Hearings Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare on Examination of the Moral and Ethical Problems Faced With the Agonizing Decisions of Life and Death*, 93d Cong., 2d Sess. 2 (1974).[29] Congress again held hearings on the subject in 1983.

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65, 5862, 5873, 5880, 5915, 6145, 7114, 7136, 7153, 18127, 24562, 24569, 24571, 24580-81, 24586-589, 29628, 29633 (1973).

[28] "Debates about the ethics of foregoing life-sustaining treatment for newborns began to appear in professional journals in the early 1970's." President's Commission at 198 n.4 (citing Duff and Campbell).

[29] This hearing was apparently merely investigative, designed to "focus public attention on these issues." Neither § 504, nor the Rehabilitation Act, was mentioned in the hearing.

S.Rep. No. 246, 98th Cong. 1st Sess. (1983), *reprinted in* [1984] U.S. Code Cong. & Adm. News 2981.[30]

It is the 1982 Infant Doe case which prompted the regulations before this Court, as well as the Child Abuse Act Amendments of 1984. P.L. 98-457. The 1984 Senate Report noted that "[t]he highly publicized recent cases have catapulted the issue of withholding treatment from seriously ill newborn infants into the public arena. . . ." S.Rep. No. 98-246, at 6.

The silence of the legislative history on the specific issue of the treatment of handicapped infants does not conclude the inquiry. Statutory interpretation is not a narrow process, tied only to the particular facts before the legislature, but is necessarily broader, since statutes look to the future. As this Court recently stated: "The fact that RICO has been applied to situations not expressly anticipated by Congress does not demonstrate ambiguity. It demonstrates breadth." *Sedima*, 105 S.Ct. at 3287. The judicial function is not to understand the past solely in its own terms, but to apply the values that the legislature adopted to new facts as they arise. It is for the judiciary to identify the sorts of evils against which the provision is directed and to apply it to their contemporary counterparts. "[C]ongressional silence, no matter how 'clanging,' cannot override the words of the statute." *Sedima*, 105 S.Ct. at 3285 n.13. When a regulatory application of a remedial statute falls within the broad sweep of the plain language and implements the purpose of the statute, the silence of the legislative history on the particular application cannot invalidate the regulation.

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[30] These hearings and the resulting Child Abuse Amendments of 1984, P.L. 98-457, 98 Stat. 1749, indicate, if anything, that the Child Abuse Amendments were intended to supplement the regulations at issue. *See* Brief of Amicus Curiae Hon. Orrin G. Hatch and Austin J. Murphy, Members of the Congress of the United States, in Support of Petitioner.

B. The 1974 and 1978 Amendments Emphasize that The Rehabilitation Act Encompasses Handicapped Infants and Medical Services.

In enacting the 1974 Amendments to the Rehabilitation Act, Congress recognized that the emphasis on employment in the definition of "handicapped individual" in the 1973 Act, 29 U.S.C. § 706(7), conflicted with the broader intent for § 504, which was not to be "limited to employment" or to "the individual's potential benefit from vocational rehabilitation services." 120 Cong.Rec. 30534, 35009.[31] The Senate and Conference Reports on the 1974 Amendments specifically stated (1) that the amended definition of "handicapped individual" was intended to reflect a prior broader intent in § 504 and to encompass discrimination in a broad range of services, in addition to employment, (2) that § 504 "was enacted to prevent discrimination" in "health services," (3) that § 504 was expressly patterned after Title VI and Title IX, and (4) that discrimination on the basis of handicap was analogous to discrimination for race or sex, because "handicapped persons" are discriminated against "when they are, in fact, handicapped (this is similar to discrimination because of race or sex) and because they are classified or labeled, correctly or incorrectly, as handicapped . . . " S.Rep. No. 93-1297, at 37-40, 120 Cong.Rec. 30534, 34725, 35010, 35016. Congress consciously compared handicap discrimination to racial and sexual discrimination. For the court of appeals to reject this analogy "is an outright disagreement with Congress' judgment and an unconstitutional act in itself." 729 F.2d at 163 (Winter, J., dissenting).[32]

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[31] The 1974 Amendments added the first sentence of subparagraph (B) to section 6(7) of the Act. P.L. 93-516, 88 Stat. 1617 (1974). *See supra* n.2.

[32] When a challenge to an agency construction of a statutory provision, fairly conceptualized, really centers on the wisdom of the agency's policy, rather than whether it is a reasonable choice within a gap left open by Congress, the challenge must fail. In such a case, federal judges—who

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The Rehabilitation Comprehensive Services, and Developmental Disabilities Amendments of 1978, P.L. 95-602, 29 Stat. 2955 (1978 Amendments), amended the Rehabilitation Act of 1973 in three relevant areas. First, a new section provided attorney's fees for "prevailing plaintiffs" under § 504. 29 U.S.C. § 794(a)(b) (1982). Second, the "remedies, procedures and rights set forth in [T]itle VI" were made available to any person discriminated against under § 504. 29 U.S.C. § 794(a)(2) (1982). Both of these amendments indicate that § 504 was intended to serve handicapped persons as a full civil rights remedy, similar to Title VI, regarding race discrimination, and to Title IX of the Education Act Amendments of 1972, 20 U.S.C. § 1681 (1982), regarding sex discrimination.

Finally, and most importantly, the 1978 Amendments created a model demonstration program for severely handicapped children, aged 0-5 years. 29 U.S.C. § 796 (1982). This is included within Title VII, governing "comprehensive services for independent living." *Id.* Title VII authorizes grants to assist states in providing "services for children of preschool age." 29 U.S.C. § 796a, 762(b)(11) (1982). The model program[33] is directed to "multiple handicapped" children who "require a full range of health-related services."

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> have no constituency—have a duty to respect legitimate policy choices made by those who do.
>
> *Chevron*, 104 S.Ct. at 2793.

[33]The bill shifted the authority for the program to the National Institute of Handicapped Research (NIHR). 29 U.S.C. § 761a. The NIHR provides grants for research and training in pediatric rehabilitation, rehabilitation and developmental care of very low birth weight infants, intervention for high risk and handicapping conditions for children up to age 3, early intervention with risk and handicapped infants, and parental decisionmaking in the treatment of newborns with disabilities. U.S. Dept. of Education, NIHR, *Program Directory* (1985)

124 Cong.Rec. 30308. The services include "infant and preschool services, such as early intervention, parent training and counseling, infant stimulation, and early identification, diagnosis and evaluation." S.Rep. No. 890, 95th Cong., 2d Sess. 25 (1978). It was expected that these services "would be attached to children's hospitals or similar facilities." *Id.* at 29.[34]

"Subsequent legislation declaring the intent of an earlier statute is entitled to great weight in statutory construction." *Red Lion Broadcasting* v. *FCC*, 395 U.S. 637, 380-81 n.8 (1969). "[W]hile the views of subsequent Congresses cannot override the unmistakeable intent of the enacting one, such views are entitled to significant weight, and particularly so when the precise intent of the enacting Congress is obscure." *SeaTrain Shipbuilding Corp.* v. *Shell Oil Co.*, 444 U.S. 572, 596 (1980).[35] The 1973 Act, the 1974 Amendments, and the 1978 Amendments are *in para materia* and "are to be taken together, as if they were one law." *United States* v. *Stewart*, 311 U.S. 60, 64 (1940), *United States* v. *Freeman*, 44 U.S. (3 How.) 556, 564 (1845).

Since Congress specifically created a model program to meet the individual medical needs of multiple handicapped infants, regulations which prohibit the denial of medically indicated treatment to such infants in federally assisted programs are reasonably related to the enabling legislation. As originally enacted, and as a part of the amended Rehabilitation Act, § 504 provides statutory authority for

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[34] "The physical and developmental problems of these infants and young children are often life-threatening to the extent that skilled management is essential. Care for the physical development of these children must take precedence over the development of educational, treatment or developmental programs." S.Rep.No. 890, at 28. Included among these model services is pediatric care. 29 U.S.C. § 762(b)(11).

[35] This Court has previously given deference to the 1974 debates and Congressional Reports as an explanation of the scope of § 504. *Alexander*, 105 at 722-23 n.24.

these regulations. Certainly, no clearly expressed, contrary legislative intent exists.

IV.

THESE REGULATIONS ARE ENTITLED TO DEFERENCE BECAUSE CONGRESS DELEGATED SUBSTANTIAL AUTHORITY TO THE AGENCY.

This Court normally accords great deference to the interpretation of the agency charged with the statute's administration. *North Haven*, 456 U.S. at 521 n.12. Where "Congress has conferred broad discretion on an agency" to implement the statute, a court must accept the agency's interpretation unless it is "manifestly unreasonable." *American Maritime Ass'n* v. *United States*, 766 F.2d 545, 560 (D.C.Cir. 1985). If the statute is silent on the precise issue, the agency's interpretation controls "unless [it is] arbitrary, capricious, or manifestly contrary to the statute." *Chevron, U.S.A., Inc.* v. *National Resources Defense Council, Inc.*, 104 S.Ct. 2778, 2783 (1984). Despite Congress's delegation of substantial authority to HHS, the court of appeals held that the regulations at issue were not entitled to deference because there was no "longstanding consistent interpretation." 729 F.2d at 154. A thorough understanding of the regulatory history, however, demonstrates that the Secretary's rulemaking has been consistent in all respects relevant to the treatment of handicapped infants.

Since 1977, the regulations under § 504 have consistently prohibited discrimination by health care providers. 45 C.F.R. Pt. 84 App. A, Subpart F (1977). The regulations at issue originated in a "Notice to Health Care Providers." 47 Fed.Reg. 26027 (1982). The Interim Final Rule, published on March 7, 1983, did "not in any way change the substantive obligations of health care providers" but applied the Title VI procedural regulations to the context of medical treatment of

handicapped infants. 48 Fed.Reg. 9630 (1983).[36] The United States District Court for the District of Columbia struck down the Interim Final Rule under the Administrative Procedure Act, 15 U.S.C. 706(2)(A). *American Academy of Pediatrics* v. *Heckler*, 594 F.Supp. 69 (D.D.C. 1983). Subsequently, the Secretary again published proposed rules on July 5, 1983. 48 Fed.Reg. 30846 (1983). A Final Regulation, issued on January 12, 1984, contained two primary changes, based upon consideration of the 17,000 comments received: (1) The Report encouraged, but did not require, hospitals to establish Infant Care Review Committees, (2) the Report required the posting of signs, following Title VI guidelines, but altered their size and location. 49 Fed.Reg. 1622 (1984) (to be codified at 45 C.F.R. Pt. 84).[37] Both the proposed and final rules stipulated that "impossible or futile acts or therapies" were not required and recognized the priority of reasonable medical decision-making. 48 Fed.Reg. 30846-47, 49 Fed.Reg. 1622. The basic principles established in the 1977 regulations, and drawn from the Title VI regulations, were applied to the treatment of handicapped newborns.

The original Notice of Intent to issue proposed rules (NIPRM) of May 1976, 41 Fed.Reg. 20296, and the subsequent Notice of Proposed Rulemaking (NPRM) of July 1976, 41 Fed.Red. 29548, do not demonstrate that HEW had a "limited view" of the scope of § 504 which excluded medical treatment. The NIPRM concerned "[involuntarily institutionalized patients] rights to receive or refuse treatment." 41 Fed.Reg. 20297, 29559 (1976). The subsequent NPRM noted that "[s]everal commentators suggested that the regulation should cover these areas and several others noted that the

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[36] The § 504 regulations previously incorporated the Title VI procedural regulations. 45 C.F.R. § 84, Subpart G (1977).

[37] Although the court of appeals viewed these changes as an inconsistency, "[a]n initial agency interpretation is not instantly carved in stone." *Chevron*, 104 S.Ct. at 2792.

Department did not have authority to regulate in this area under section 504." *Id.* The Department concluded:

> The proposed regulation takes the same position as the draft regulation appended to the May 17 notice; i.e., there are no provisions concerning adequate and appropriate psychiatric care or safe and humane living conditions for persons institutionalized because of handicap . . . The Secretary is of the opinion that to promulgate rules on these subjects is beyond the authority of section 504.

Id.

The Department's position in that context has little in common with the present regulations. First, regulations requiring affirmative habilitative, psychiatric, or therapeutic treatment are substantively different from regulations prohibiting discrimination against handicapped infants. The Secretary accordingly distinguished the 1977 position in promulgating the current regulations. 49 Fed.Reg. 1636 (1984). Second, HEW could reasonably conclude that § 504 did not mandate a right to affirmative treatment of institutionalized persons because, by its nature, § 504 requires equal treatment of similarly situated handicapped and nonhandicapped persons. In the case of institutionalized persons, it is difficult to identify nonhandicapped persons with whom a comparative analysis can be made. But in the case of handicapped infants, a meaningful medical comparison can be made with nonhandicapped infants regarding the provision of beneficial treatment. *See* Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma 'Experiment,'* 1 Issues in Law & Medicine 15, 48-50 (1985).[38] Accordingly, HEW's conclusion

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[38] Even if the situations are analogous, this Court has held that institutionalized persons *have* a right to medical treatment. *Youngberg* v. *Romeo*, 457 U.S. 307 (1982). The state "conced[ed] that [Romeo] [had] a right to adequate food, shelter, clothing, and medical care" and this Court concluded that Romeo had a right to safe conditions, freedom from bodily restraint, and

(footnote continued on next page)

that § 504 did not mandate affirmative habilitative or psychiatic care for institutionalized persons is simply irrelevant to the issue of the authority under § 504 to proscribe intentional discrimination in the failure to provide medically-indicated treatment to handicapped newborns. It was erroneous, therefore, for the court of appeals to conclude that HEW's position established a "limited" view of § 504 that in any sense reflects upon the present regulations.[39] In addition, the court of appeals failed to understand the purpose of HEW's conclusion that the regulation would not "require specialized hospitals and other health care providers to treat all handicapped persons." 729 F.2d at 152. By this, HEW meant that a health service provider would not have to provide treatment to handicapped persons if it did not provide such treatment to nonhandicapped persons, or did not

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(footnote continued from preceding page)

"minimally adequate or reasonable training to ensure safety and freedom from undue restraint." *Id.* at 315-319. This Court held that "the Constitution only requires that the courts make certain that professional judgment in fact was exercised. It is not appropriate for courts to specify which of several professionally acceptable choices should have been made." *Id.* at 321. Nevertheless, it is implicit that, if Romeo had a right to adequate food, shelter, clothing, medical care, etc., then "professional judgment" or "professionally acceptable choices" could not include denying these basic rights.

[39] The court also concluded that these regulations were contradicted by § 1395 of the Medicare Act and § 1320(c) of the Social Security Act (PSRO), passed prior to § 504. 729 F.2d at 160. These statutes, however, are not *in para materia*. They cannot be construed together because they do not concern the same subject matter, *United States* v. *Stewart*, 311 U.S. 60, 64 (1940), or have the same purpose, *Erlenbaugh* v. *United States*, 409 U.S. 239, 245-46 (1972), and were not enacted in the same time period, much less simultaneously. *Dickerson* v. *New Banner Institute, Inc.*, 103 S.Ct. 986, 994 (1983). They have neither similar language, *Oscar Mayer Co.* v. *Evans*, 441 U.S. 750 (1979), nor identical coverage, *Tooahnippah (Goombi)* v. *Hickel*, 397 U.S. 598, 606 (1970).

have the proper facilities, but if it provided a type of treatment to nonhandicapped persons, it could not refuse such treatment to handicapped persons. Thus, for example, the burn center cannot "refuse to treat the burns of a deaf person because of his or her deafness." 45 C.F.R. Pt. 84, App. A, Subpart F, ¶ 36 (1977).

In addition, although the court noted that the proposed version of the 1977 regulations "emphasized the availability of services," 729 F.2d 152 (citing 41 Fed.Reg. 29567 (1976)), it failed to note that the proposed rules equally emphasized the "level of services."[40] In concluding that HHS had made a "shift in agency policy" by promulgating the present "novel and far-reaching regulations, the court ignored the fact that HHS, under the Carter Administration, had taken the same position. Pet. for Cert. at 24, 48 Fed.Reg. 30847-48 (1983). *See Protection and Advocacy Agency of Hawaii* v. *Kapiolani Children's Hospital*, Health and Human Services Doc. No. 09-79-3158 (1980).[41]

These regulations, like prior regulations promulgated under § 504, are entitled to substantial deference. *Alexander*, 105 S.Ct. at 722 n.24. The 1974 Amendments emphasized that the responsibility for regulations was delegated to

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[40] "All health services shall be provided to handicapped persons at least to the same extent that they are provided to nonhandicapped persons and shall be provided in such manner as is necessary to afford handicapped persons equal opportunity to benefit from these services." 41 Fed.Reg. 29567 (1976).

[41] In *Chevron*, this Court upheld regulations where the legislative history was "silent on the precise issue," 104 S.Ct. at 2792, the agency had changed its interpretation of the statutory term, *Id.*, and the current administration had reversed the previous administrative interpretation, *Id.*, at 2789, because the current interpretation was consistent with the legislative policy concerns and Congress had delegated substantial authority. Here, the regulations are also consistent with policy concerns and the current regulations emphasize a position adopted by an earlier administration.

HEW. S.Rep. No. 1297, at 39-40.[42] The 1974 Amendments "clarified the scope of § 504 by making clear that those charged with administering the Act had substantial leeway to explore areas in which discrimination against the handicapped posed particularly significant problems and to devise regulations to prohibit such discrimination." *Alexander*, 105 S.Ct. at 722-23 n.24. Furthermore, the 1978 Amendments were intended to codify the regulations enforcing § 504. *Id.*, *Darrone*, 104 S.Ct. at 1254-55 n.15-16.

Since Congress intended § 504 to establish a comprehensive, federal policy of nondiscrimination, Congress did not expect § 504 to be dependent on state law. *Cf. North Dakota*, 103 S.Ct. at 1104, *Dickerson*, 103 S.Ct. at 995, *NLRB* v. *Natural Gas Utility Dist.*, 402 U.S. 600, 603 (1971). Congress evidently showed that it expected HEW to administer regulations under § 504 with the same authority that it does so under Title VI. *Cf. Lau* v. *Nichols*, 414 U.S. 563, 569 (1974). The regulations at issue should likewise be accorded substantial deference.

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[42] After noting that 504 was "patterned after" Title VI and "therefore constitut[ed] the establishment of a broad governmental policy against handicap discrimination," the 1974 Senate Report stated that 504 "does not specifically require the issuance of regulations or expressly provide for enforcement procedures, but it is clearly mandatory in form, and such regulations and enforcement are intended." The language of 504 "envisions the implementation of a compliance program which is similar to [Titles VI and IX], including promulgation of regulations providing for investigation and review of recipients of Federal financial assistance...." Congress intended that 504 "be administered in such a manner that *a consistent, uniform and effective Federal approach* to discrimination against handicapped persons would result," and gave the Secretary of HEW "responsibility for coordinating the section 504 enforcement effort...." S.Rep.No. 1297, at 39-40 (emphasis added).

V.

CONCLUSION

For the foregoing reasons, the judgment of the court of appeals below should be reversed.

Respectfully submitted,

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No. 84-1529

IN THE
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OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF GEORGE P. SMITH, II, CATHOLIC UNIVERSITY SCHOOL OF LAW

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ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF GEORGE P. SMITH, II, CATHOLIC UNIVERSITY SCHOOL OF LAW

This brief is filed with the writen consent of the parties; the consents are lodged with the Clerk of this Court.

INTEREST OF THE AMICUS CURIAE

The *amicus curiae* is a widely regarded teacher and scholar in the field of Health Law – having begun his study and writing in 1968.[1] As Faculty Editor-in-Chief of

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[1]Smith, Through A Test Tube Darkly: Artificial Insemination and The Law, 67 MICH. L. REV. 127 (1968); cited in *Roe v. Wade*, 410 U.S. 113, 161 (1973), per Blackmun, J.

The Journal of Contemporary Health Law and Policy, published by The Catholic Univesity Law School in Washington, D.C., and as an international lecturer who – among other appointments – has been a Fulbright Visiting Professor of Law and Medical Jurisprudence at the University of New South Wales in Sydney, Australia, in 1984, and in such capacity lectured throughout the Continent of Australia on matters of current Health Law, the *amicus* has established a record of both vital concern and commitment to not only promoting and maintaining the public welfare through the maintenance of high professional standards, but the continued development and assurance of quality health care for all citizens – regardless of their mental or physical condition.

The interest of the *amicus curiae* is not in extending the philosophical, ethical, moral or religious debate surrounding the central issue of qualify of life *versus* sanctity of creation. Rather, his interest is in placing these issues and concerns, where appropriate, within a full and objective framework for principled analysis; a framework that first and foremost embodies a recognition of the extent to which a balance is maintained between the state and the federal government's obligation to protect all of its citizens from abuse or discrimination regardless of age or physical weakness. And, furthermore, a framework that recognizes any intrusion into familial privacy must be tied either to a standard of reasonableness or what is in the best interests of the particular handicapped individual.

The outcome of this case will directly affect and, indeed, shape the future of the law for handicapped individuals of all ages by clarifying the extent to which the most significant civil right of all – the right to life – is assured for individuals born with a handicap. Thus, it is of critical

importance to those scholars and teachers who specialize in the field and who – as such – analyze, interpret, assist and chart new directions of needed law reform, that an academic perspective be presented here.

For these reasons, the *amicus* wishes respectfuly to present his views regarding the complex issues raised by the regulations and interpretative guidelines for handicapped newborns published January 12,1984, by Margaret M. Heckler, Secretary of the United States Department of Health and Human Services, under the alleged authority of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794.

SUMMARY OF ARGUMENT

The *amicus curiae* submits this brief in support of the American Hospital Association, et al., Respondents.

Congress enacted the Rehabilitation Act of 1973 and the subsequent amendments in order to foster vocational rehabilitation programs and encourage integration of handicapped individuals into the work force. To the extent that employment goals were to be supervised, Congress intended Section 504 of the Act as but a broad mandate to allow *access* for handicapped individuals to all federally funded programs and institutions. Furthermore, Congress did not intend to impose an affirmative action obligation on all recipients of federal funds beyond that of non-discrimination on the basis of handicap.

Nowhere in the Rehabilitation Act, itself, nor in its legislative history, is there either a reflection or a specific Congressional mandate for the United States Department of Health and Human Services – or any other Depart-

ment – to intrude into the familial decision making process or contravene medical care decisions which parents make for their newborn, albeit handicapped, infants. The Department, however, seeks to utilize Section 504 of this Act as a vehicle for intervention in health care decision making within the family by its promulgation of implementing regulations and interpretative guidelines. These actions are totally inconsistent with the stated purpose of the Act as articulated by Congress and interpreted by the Courts. Thus, they should be considered as *ultra vires.*

Consistent with long cherised principles of Federalism, Congress and the individual states have already acted with purpose and resolve in addressing the very issue of child protection that these presently contested federal regulations do; this action they have taken through the promotion and enactment of Child Abuse Prevention and Protection Acts. This body of law is sufficient to deal with the very problems that the United States Department of Health and Human Services seeks to rectify with these federal regulations.

Finally, the promulgation of these contested Section 504 regulations and interpretative guidelines intrudes directly into the familial right of privacy to not only be left alone in making reasonable judgments regarding the health of their children but to an entitlement to withhold information regarding the bases for these judgments.

ARGUMENT

I. THE CONGRESSIONAL PURPOSE OF THE 1973 REHABILITATION ACT DOES NOT EXTEND BEYOND THE VOCATIONAL AND EMPLOYMENT GOALS THAT CONGRESS SET FORTH.

Citing the failure of the basic vocational rehabilitation programs to respond to the needs of handicapped individuals and the lack of alternative services within communities to assist these individuals, Congress set forth corrective legislation in what became the 1973 Rehabilitation Act.[2] This Act was enacted as Public Law 93-112, 87 Stat. 355, to provide a statutory basis for the Rehabilitation Services Administration and to authorize programs of various kinds to benefit handicapped individuals.[3]

Congress declared the purpose of the 1973 Rehabilitation Act to be one of providing for vocational rehabilitation services to handicapped individuals. Accordingly, the Rehabilitation Services Administration was empowered to conduct surveys and to develop methods for providing rehabilitative services – including assistance in construction of facilities, in order to meet the present and future vocational needs of these individuals.[4] To the extent that the Congressional purpose was to extend further, and into the area of medicine, the mandate was simply to:

> ". . . develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated pro-

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[2] S. REP. NO. 93-318, 93rd CONG., 1ST SESS., reprinted in 1973 U.S. CODE CONG. & AD. NEWS 2076, 2075.

[3] *Id.*

[4] 29 U.S.C. § 720a (1982).

grams of vocational rehabilitation and independent living."[5]

There can be no question of the clarity of the Congressional intent: to promote the development of technology to such an extent that the resources available to the handicapped would increase and in turn foster employment opportunities for them. Nowhere in the Act nor in its history is to be found a mandate by Congress requiring handicapped individuals to partake in that which is being made accessible to them. Moreover, at no place in the Act does Congress suggest any sort of intervention into medical decision making. The express goals of Congress were broad only insofar as vocational rehabilitation for the handicapped individuals were concerned. It was understood, implicitly, that handicapped individuals would in due course avail themselves of these facilities and programs. Yet, in order for this opportunity to be protected, Congress found it necessary to provide for these very same individuals a private cause of action under which their rights could be asserted. Section 504 of The Rehabilitation Act has been construed consistently as the vehicle by which a handicapped person may require federally funded programs and institutions to be made accessible to them.[6]

A. IN FURTHERANCE OF THE VOCATIONAL GOALS OF THIS ACT, CONGRESS INTENDED SECTION 504 TO PROVIDE ABSOLUTE ACCESS FOR HANDICAPPED INDIVIDUALS TO ALL FEDERALLY FUNDED PROGRAMS AND INSTITUTIONS BY PROVIDING A PRIVATE CAUSE OF ACTION.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, constituted the establishment of a broad govern-

[5]29 U.S.C. § 701 (1982).

[6]Lau v. Nichols, 414 U.S. 563 (1974).

mental policy that programs receiving federal financial assistance should be operated without discrimination on the basis of handicap.[7] This language is patterned after the comparable provisions of the Civil Rights Act of 1962, 42 U.S.C. § 2000d and Title IX of the Education Amendments of 1972, 20 U.S.C. § 1681. The Statute was amended in 1978 in order to extend the benefits of Section 504 to handicapped individuals under any program or activity conducted by an executive agency or by the United States Postal Service and to require each such agency to promulgate regulations made necessary to carry out the amendments thereto.[8]

The courts have construed Section 504 of the Rehabilitation Act of 1973 consistently as having conferred on those persons intended to be protected affirmative rights that – by implication – may be vindicated by maintenance of a private cause of action.[9]

This court has already spoken to the need for clear guidelines limiting private causes of action when a statute so provides. In *Court v. Ash,* 422 U.S. 66 (1975), this Court decided that regulations implementing a statute that is intended to provide a private cause of action in persons intended to be covered thereby must be limited. The decision in *Court,* outlines four basic questions to be posited when reviewing such implementing regulations:

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[7]Lloyd v. Regional Transp. Auth., 548 F.2d 1277 (7th Cir. 1977).

[8]Rehabilitation, Comprehensive Services & Developmental Disabilities Act of 1978, Pub. L. 95-602, 92 Stat. 2982, codified as 29 U.S.C. § 701 et seq. (1982).

[9]See e.g., Kampmeier v. Nyquist, 553 F.2d 296 (2d Cir. 1977); United Handicapped Federation v. Andre, 558 F.2d 413 (8th Cir.1977).

> "First, is the plaintiff 'one of the class for whose especial benefit the statute was enacted'; Second, is there any indication of legislative intent, explicit or implicit, either to create such a remedy or to deny one; Third, is it consistent with the underlying purposes of the legislative scheme to imply such a remedy for the plaintiff; and . . . Fourth, is the cause of action one traditionally relegated to state law in an area basically the concern of the States, so that it would be inappropriate to infer a cause of action based solely on federal law?"[10]

In this present appeal, the petitioner is not one of the class for whose especial benefit the Rehabilitation Act of 1973 was enacted. Neither the handicapped individual nor the parents involved in this appeal seek any type of redress. Indeed, in both cases below, the United States Secretary of Health and Human Services sought to initiate action – clearly a plaintiff not contemplated as such in the class. Had the parents sought and been denied access to the hospital in the instant case, they would have clearly been within the class of plaintiffs contemplated to seek remedial action bsed on the Rehabilitation Act – but, again, not the Department of Health and Human Services.

As to the second *Ash* question, nowhere in the congressional history of the Rehabilitation Act of 1973 can be discerned a legislative intent for the creation of the remedy sought herein. The HHS regulations are overbroad and intrusive insofar as the medical decision making process is concerned. Moreover, the facts in this instant case demonstrate that the facilities of the hospitals in question were at all times accessible to everyone. That the parents decided

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[10]422 U.S. 66, 78 (1975).

not to use the federally funded facilities as available is a wholly separate issue that does not implicate the hospital, itself, or its "discrimination" on the basis of handicap. The legislative intent of Section 504 calls for absolute *access* to federally funded programs. It does not extend to the remedy of federal intervention by way of HHS regulations abrogating the rights of parents in medical decision making.[11]

Applying the third *Ash* question to the present appeal, it is seen that the questioned regulations issued under the grant of Section 504 of the Rehabilitation Act of 1973 are inconsistent with the underlying purposes of the legislative scheme to imply such a remedy for the plaintiffs. Forced federal intrusion into the family decision making process goes beyond facilitating a private cause of action for the families.[12]

Finally, testing the fourth *Ash* factor or question with the facts of this present appeal, it is seen clearly that the cause of action here is one that is traditionally relegated to state law in an area basically the concern of the state as is obvious from the long history of attention paid by them to the problem of child abuse and prevention.[13] Indeed, each of the fifty states and the District of Columbia has enacted legislation designed specifically to provide for a duty to report and a remedy to investigate, take custody and pro-

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[11]See e.g., 45 C.F.R. 84.55(f)(3)(D).

[12]See generally, 45 C.F.R. 84.55.

[13]See 45 C.F.R. 84.55(b)(5).

secute when necessary incidents of child abuse occur.[14] Should denial of consent by parents rise to the level of child abuse or neglect, the provisions of these laws are strong enough to deal with the problem.[15] Moreover, the HHS regulations at issue in this case refer to the existence of this body of jurisprudence and attempt to, in essence, duplicate all the work that has been done and is being done

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[14]Ala.Code §§26-15-1-26-15-4 (1975); Alaska Stat. §47.10.010 (1962); Ariz.Rev.Stat.Ann. §13.3673 (1956); Ark.Stat.Ann. §42-807 (1977); Cal.Penal Code §11165 (West 1980), Colo.Rev.Stat. §18-6-401 (1973); Conn.Gen.Stat. §53-20 (1949); Del.Code Ann.tit. 31, §301 (1974); D.C.CodeAnn. §6-2101 (1981); Fla.Stat. §827.07 (1981); A.CodeAnn. §74-111 (1933); Hawaii Rev.Stat. §350-1 (1976); IdahoCode §16-1601 (1949); Ill.Rev.Stat.ch.23, §2368 (1977); Ind.Code Ann. §31-6-11-1 (Burns 1980); IowaCode §235 (1979); Kan.Stat.Ann. §38-704 (1965); Ky.Rev.Stat. §15-900 (1984); La.Rev.Stat.Ann. §14.93 (West 1970); Me.Rev.Stat.Ann.tit. 19 §218 (1964); Md.Pub. Safety Code Ann. §35A (1973); Mass.Gen.Laws Ann.ch. 273 §1 (West 1975); Mich.Comp.Laws Ann. §722.622 (West 1983); Minn.Stat.Ann. §626.556 (West 1962); Miss.Code Ann. §43.19.1 (1972); Mo.Rev.Stat. §210.110 - 210.165 (1982); Mont.Code Ann. §10-503 (1977); Neb.Rev.Stat. §28-707 (1979); Nev.Rev.Stat. §§200.501 - 200.509 (1973); N.H.Rev.Stat.Ann. §169.38 (1955); N.J.Stat.Ann. §26.24-4 (West 1982); N.M.Stat.Ann. §30-6-1(c) (1978); N.Y.Social Services Law §412 (McKinney 1983); N.C.Gen.Stat. §14-318.2 (1981); N.D.Cent.Code §50-25.1-02 (1982); Ohio Rev CodeAnn. §29.1922 (1982); Okla.Stat.Ann.tit.21 §843 (West 1983); Or.Rev.Stat. §418.770 (1983); Pa.Stat.Ann.tit.11 §23 (Purdon 1965); R.I.Gen.Laws §40-11-2 (1956); S.C.CodeAnn. §20-7-10 (Law.Co-op 1976); S.D.Codified Laws Ann. §26-10-10 (1984); Tenn.CodeAnn. §37-1200 (1977); Tex. Family Code Ann. §35.04 (Vernon 1975); Utah Code Ann. §76-5-109 (1953); Vt.Stat.Ann.tit.13 §2801 (1974); Va.Code §63.1.248 (1950); Wash.Rev.Code §26.44.020 (1974); W.Va.Code §49-1-3 (1980); Wis.Stat.Ann. §940.201 (West 1982); Wyo.Stat. §6-4-504 (1977).

[15]*Id.* See Smith, Long Days Journeys Into Night: The Tragedy of The Handicapped At Risk Infants, in MORAL ISSUES IN MENTAL RETARDATION Ch. 8, (R.Laura, ed. 1984).

at the state levels.[16] Thus, these HHS regulations are not only unnecessary and duplicative of what is presently being done, but are beyond the scope of what has been intended by Congress and, thus, *ultra vires.*

B. THE HHS REGULATIONS IMPOSE AN AFFIRMATIVE ACTION OBLIGATION ON RECIPIENTS OF FEDERAL FUNDS BEYOND THE SCOPE OF WHAT CONGRESS INTENDED FOR SECTION 504.

The legislative interpretation of the mandate of Section 504 is difficult to discern from its history. In fact, the only information provided in the explanation of this mandate is found in one simple sentence:

> "This section prohibits discrimination, exclusion or denial of benefits to otherwise qualified handicapped individuals by any program or activity receiving Federal financial assistance." 1973 U.S. Code Cong. & Ad. News at 2143.

Congress relied, apparently, on the assumption that Section 504 would be enforced as had previous civil rights legislation and, thus, set forth no language in the statute – itself – requiring rule making. There is no indication, therefore, that Congress ever intended to impose affirmative action obligations on all recipients of federal funds.

Enforcement provisions were, however, necessary. Thus, on April 28, 1976, President Ford ordered the then United States Department of Health, Education and Welfare (now Health and Human Services) to "establish standards for determining what are discriminatory practices

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[16]See 45 C.F.R. 84.55(b)(5).

within the meaning of § 504."[17] The Order charged the Department of Health and Human Services (HHS) with co-ordinating and implementing Section 504 and required other federal agencies to issue Section 504 regulations consistent with HHS standards.

The first set of regulations were issued on May 4, 1977, with an apparent attempt to fit the problem of discrimination against the handicapped into the model of the remedy for race discrimination, that one court likened it to "fitting a square peg into a round hole."[18] What followed as a consequence of this action was a plethora of new federal regulations designed to prevent discrimination on the basis of handicap in programs and activities receiving or benefitting from federal financial assistance.[19]

The instant case is concerned primarily with an overextension of the HHS regulatory powers pursued as such under the guise of implementing Setion 504 of the Rehabilitation Act through the promulgation of regulations designed to protect handicapped newborns from discri-

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[17]Executive Order No. 11,914, April 28, 1976, reported in 29 U.S.C. §294 (1976 Supp.), revoked by Executive Order No. 12, 250 issued Nov. 2, 1980, reprinted as a note to 42 U.S.C. §2000d-1 (1980 Supp.) at 199-200.

[18] Garrity v. Gullen, 522 F. Supp. 171, 206 (D.N.H. 1981).

[19]For applications of this regulations, see: Agency for International Development, 22 C.F.R. 217.1 (1984); Department of Agriculture, 7 C..F.R. 15b.1 (1985); Department of Commerce, 15 C.F.R. 8b.1 (1984); Department of Defense, 32 C.F.R. 56.1 (1984); Department of Education, 34 C.F.R. 104.1 (1984); Department of Health & Human Services, 45 C.F.R. 84.1 (1984); Department of Labor, 29 C.F.R. 32.1 (1984); 41 C.F.R. 29-70.100 (1984); Department of State, 22 C.F.R. 142.1 (1984); Department of Interior, 43 C.F.R. 17.200 (1984); National Endowment for the Humanities, 45 C.F.R. 1170.1 (1984); National Science Foundation, 45 C.F.R. 605.0 (1984); Veterans Administration, 38 C.F.R. 18.1 (1984).

mination in the delivery of health care services in hospitals receiving federal funds. Congress intended for HHS, as well as all other Departments and Agencies, to assist in assuring *access* for handicapped individuals to a variety of federally funded programs,[20] and not the *delivery* of health services.

In the stated purpose of the HHS regulations that are being challenged presently, it is recognized that they were promulgated to ostensibly implement Section 504 of the Rehabilitation Act, yet – interestingly – Infant Care Review Committees (ICRC) – were advocated as a means to ". . . assist in making decision concerning medically beneficial treatment in specific cases." 45 C.F.R. 84.55. Nowehere in its history has Section 504 been interpreted as extending an invitation for federal intervention into the medical decision making process for infants or anyone else. These regulations clearly go beyond the scope of implementing Section 504 which was, originally, enacted to assure *access* to programs (including medical care in federally funded hospitals) but *not to force treatment* by a federal government procedure of intervention into the medical decision making process.

It is recognized that an administrative agency is only empowered to make rules consistent with the authority granted it by a particular grant of statutory delegation.[21] When regulations and rules are made outside the statutory power conferred, they are to be challenged as being *ultra vires.*[22] And, thus, the actions of Margaret M. Heckler, the Secretary of Health and Human Services, in promul-

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[20]Drennon v. Philadelphia Gen. Hosp., 428 F.Supp. 809 (E.D. Pa. 1979).

[21]B. SCHWARTZ, ADMINISTRATIVE LAW §4.4 (2d ed. 1984).

[22]*Id.*

gating the regulations and interpretative guidelines at issue here on January 12, 1984,[23] are invalid inasmuch as they have no rational relationship to the governing statute — the Rehabilitation Act of 1973.

In *Southeastern Community College v. Davis,* 442 U.S. 397 (1979), the Court further clarified the purpose of Section 504. In holding that the plaintiff's rejection to nursing school on the basis of her hearing impairment was not protected by Section 504, the Court stated that the statutory mandate of providing access to federally funded programs and institutions is statutorily limited by the phrase, "an otherwise qualified" person. Moreover, the court found these implementing regulations should be written narrowly in such a manner so as not to constitute "an authorized extension of obligations by [that statute]."[24]

In addressing the issue of what reach HHS implementing regulations may have, the Court continued in *Southeastern* to state:

> "Although an agency's interpretation of the statute under which it operates is entitled to some deference, 'this deference is constrained by our obligation to honor the clear meaning of a statute, as revealed by its language, purpose and history.' *Teamsters v. Daniel,* 439 U.S. 551, 556 n. 20 (1979). Here, neither the language, purpose nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds."[25]

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[23]49 Fed. Reg. 1622.

[24]442 U.S. 397, 410 (1979).

[25]*Id.* at 411.

Here, in the instant case, these HHS regulations continue to impose an affirmative action obligation on recipients that was not contemplated by Congress. The Court has maintained consistently that when "Congress intends to impose a condition on the grant of federal moneys, it must do so unambiguously." *Pennhurst State Hospital v. Halderman,* 451 U.S. 1, 17 (1981). To the extent that Section 504 is involved, Congress has made no such mandate.

II. INASMUCH AS THE STATES HAVE ALREADY ENACTED CHILD ABUSE AND PROTECTION LEGISLATION, THE REGULATIONS AND INTERPRETATIVE GUIDELINES ENACTED BY THE UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES IN THIS AREA OF CONCERN, ARE UNNECESSARY, REDUNDANT AND INTRUSIVE.

The Congressional mandate for affirmative action conduct which is not found in Section 504 of the 1973 Rehabilitation Act is found in each state's Child Abuse Prevention Acts[26] as well as the Federal Child Abuse Prevention and Treatment Act, 42 U.S. § 5101 (1982). These enactments impose a standard of affirmative action conduct on the part of the individuals and institutions to report incidents of child abuse and/or neglect. The Indiana legislation in this area is illustrative of the extent to which affirmative action is required in that it imposes a duty to report upon "any individual who has reason to believe that a child is a victim of child abuse or neglect. . . ." IND.CODE ANN. § 31-6-11-3 (Burns 1980). In addition to these protections that are afforded infants, the medical profession – itself – imposes a self-regulatory duty upon

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[26] *Supra* note 14.

its physicians to maintain respect for all human life through adherence to the Hippocratic Oath.[27]

The federal government assistance in this area is more than adequate to safeguard the health and welfare of its citizens and prevent discrimination.[28] Additionally, pursuant to Sections 1152(a) and 1154 of the Social Security Act, (42 U.S.C. §§ 1302, 1320c-4(a)(7) (1982), HHS has established the Professional Standards Review Organization for the purpose of reviewing the work of both physicians and hospitals. 42 C.F.R. 463, 466.

A. UNDER THE DOCTRINE OF FEDERALISM, IT IS FOR THE STATE AND THE FEDERAL GOVERNMENTS TO REACH A FLEXIBLE ACCOMMODATION OF MUTUAL INTERESTS IN THE FIELD OF HEALTH CARE AND MAINTENANCE. THIS ACCOMMODATION HAS BEEN ACHIEVED WITHOUT THE NEED OR REFERENCE TO THE CHALLENGED SECTION 504 REGULATIONS.

At the constitutional level, absolutes are needed not only to preserve greater aspirations and ideals, but to "keep us from foolhardy action where wrong results really matter."[29] There is no greater aspiration or ideal than that seen in the principles of creative federalism whereby the

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[27]Oath of Hippocrates, 5th Century B.C. as reprinted in J. KATZ, EXPERIMENTATION WITH HUMAN BEINGS 311 (1972). See also, the re-formulation of the Oath by the World Medical Association in KATZ, at 312.

[28]*Supra* note 19.

[29]G. CALABRESI, A COMMON LAW FOR THE AGE OF STATUTES 179 (1982).

state and the federal government achieve "a flexible and dynamic accommodation of conflicting interests."[30]

The maintenance of health care service and the assurance of accessibility to those services without discrimination to the users is a first line responsibility of the states. And, to their credit, they have in the past, and continue so today, through various specific legislative programs, to provide both non-discriminatory access to health care services for all – regardless of age or mental or physical handicap.[31] And, the federal government, much to its credit, has mandated that all federally funded health care facilities provide non-discriminatory *access* to these facilities,[32] and – furthermore – that there be no discrimination on the basis of handicap in programs and activities receiving or benefiting from federal financial assistance.[33] It is here, then a "flexible accommodation" is both met and achieved between the states and the federal government without any offensive intrusion by one into the other.

In *United States v. University Hospital, State University of New York at Stony Brook, et al.*, Circuit Judge Pratt, writing for the majority, stated that no presumption could

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[30]O'Connor, Our Judicial Federalism, 35 CASE W. RES. L. REV. 1, 12 (1984-85).

The concept of "our federalism," observed Mr. Justice Hugo Black, is that it is "a system in which there is sensitivity to the legitimate interest of both State and National Governments, and in which the National Government, anxious though it may be to vindicate and protect federal rights and federal interests, always endeavors to do so in ways that will not unduly interfere with the legitimate activities of the State." *Younger v. Harris,* 401 U.S. 37 (1971).

[31]*Supra* note 14.

[32]See 50 Fed. Reg. 14878 (April 15, 1985); Federal Child Abuse Prevention and Treatment Act, 42 U.S.C. §5101 et seq. (1982).

[33]*Supra* note 19.

be indulged which allowed Congress, in enacting Section 504,

> "to enter the field of child care, which, as HHS has recently acknowledged, has traditionally been occupied by the states. See 49 Fed. Reg. 1626-27, 1629-31; 48 Fed. Reg. 9630. Had Congress intended to displace state police power functions, it surely would have made that intention explicit."[34]

On January 9, 1985, a unanimous decision by the United States Supreme Court acknowledged that:

> "In enacting the Rehabilitation Act and in subsequent amendments, Congress did focus on several substantive areas – employment, education, and the elimination of physical carriers to access – in which it considered the societal and personal costs of refusals to provide meaningful access to the handicapped to be particularly high. But nothing in the pre- or post-1973 legislative discussion of § 504 suggests that Congress desired to make major inroads on the States' longstanding discretion to choose the proper mix of amount, scope and duration limitation on services. . . ." *Alexander et al. v. Choate et al.*, ____ U.S. ____, 105 S. Ct. 712, 724 (1985).

B. SOUND PRINCIPLES OF JUDICIAL AND LEGISLATIVE INTERPRETATION DIRECT A NEGATION OF THE PRESENT SECTION 504 REGULATIONS AND INTERPRETATIVE GUIDELINES.

While the original Constitution was concerned with – essentially – developing and ensuring mechanisms for

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[34]729 F.2d 144 160 (2d Cir. 1984).

democratic choice, today constitutional scholarship "is dominated by the creation of arguments that will encourage judges to thwart democratic choice."[35] Consequently, it remains for the modern court to strive to both grasp and to understand the distinctive meaning of statutory words as they are set out in their own individual context – with full reference to the documented processes that produced them.[36]

Judicial construction should adhere to what has been said by the legislature and "not draw prodigally upon unformulated purposes or directions."[37] Indeed, it has been posited that the major – if not sole – task for a contemporary judge is to avoid the infusion of extra-constitutional moral and political norms into his deliberative processes;[38] and, rather, to seek and thereby translate the legislative morality of a questioned statute into a practical rule.[39]

The doctrine of *casus omissus* is clear: if a legislative omission occurs within a statute, causing a resulting gap, a court can neither supply the omission nor fill the gap.[40] The clarity of this doctrine goes to underscore the responsibility of the judiciary to follow a path of strict construc-

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[35]Bork, Tradition and Morality in Constitutional Law at 9 (1984), The Francis Boyer Lecture on Public Policy, American Enterprise Institute, Washington, D.C.

[36]J. HURST, DEALING WITH STATUTES 65 (1982).

[37]Frankfurter, A Symposium on Statutory Construction, 3 VAND. L. REV. 265, 367 (1950).

[38]*Supra* note 35 at 3.

[39]*Id.* at 11.

[40]R. DICKERSON, THE INTERPRETATON AND APPLICATION OF STATUTES 216 (1975).

tion – especially so when the meaning of a questioned statutory text is plain, clear or unambiguous.[41]

It is patently clear from the words of the Rehabilitation Act of 1973 – let alone the legislative history – that both the Act, and in particular Section 504, have no concerns with the treatment of handicapped newborns in federally funded hospitals. Even if there were to have been a legislative omission here (of which there was none), the Court is restrained from providing corrective assistance.

In analyzing the post enactment legislative history of Section 504, Circuit Judge Pratt found unequivocal indications that,

> "congress was primarily concerned with affording the handicapped access to federally-funded programs and activities, and that Congress never envisioned that HEW (or HHS) would attempt to apply section 504 to treatment decisions." *United States v. University Hospital, State University of New York at Stony Brook, et al.*, 729 F.2d 144, 159 (2d Cir. 1984).

Mr. Justice Marshall, writing for a unanimous Court, stated that when seeking an interpretation of Section 504, two "countervailing considerations" need to be understood and be responded to properly: "the need to give effect to the statutory objective and the desire to keep § 504 within manageable bounds." *Alexander et al. v. Choate et al.*, ___ U.S. ___, 105 S. Ct. 712, 720 (1985).

> "Given the legitimacy of both of these goals and the tensions between them, we decline the parties' invitation to decide today that one of these goals so overshadows the other as to be

[41]C. SANDS, 2A STATUTES AND STATUTORY CONSTRUCTION §46.04 (4th ed. 1973).

eclipsed." *Alexander et al., supra,* at 105 S. Ct. 712, 720 (1985).

Both the stated objects of the Rehabilitation Act of 1973 and the scope of Section 504 of that Act would be thwarted and made *totally unmanageable* by the validation of the regulations and interpretative guidelines issued by Secretary Heckler in this present appeal.

III. THE FAMILIAL RIGHT OF PRIVACY ALLOWS FOR A CO-ORDINATE RIGHT OF PARENTS TO MAKE JUDGMENTS REGARDING THE HEALTH AND WELL-BEING OF THEIR MINOR CHILDREN ACCORDING TO A STANDARD OF REASONABLENESS OR WHAT, TRADITIONALLY IS IN THE BEST INTERESTS OF THE CHILD.

The preservation of the family unit has been recognized as an important societal goal[42]; and a worthy and proper area for the state to undertake efforts to ensure that children are raised in a stable and traditional family setting.[43] Indeed, substantial evidence suggests that it is in a child's best interest to have a family.[44] Thus, even though the most universal relation in nature is to be found between parent and child there is a discernible modern legislative trend toward replacing the traditional deference to parental authority, with a new emphasis on child welfare.[45]

In 1973, the dominant judicial attitude in settling disputes conc ning children was to inquire whether the

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[42]Quillon v. Walcott, 98 U.S. 549, 555 (1978).

[43]Smith & Iraola, Sexuality, Privacy and The New Biology, 67 MARQ. L. REV. 263, 290 (1984).

[44]L. TRIBE, AMERICAN CONSTITUTIONAL LAW 84 (1979 Supp.).

[45]Dickens, The Modern Function and Limits of Parental Rights, 97 L.Q. REV. 462 (1981).

best interest or welfare of the child would be served. In 1979, however, a neo-conservative attitude was advocated, and is gaining respect, which directs judicial restraint and discourages state intervention when "children issues" arise.[46] As one commentator has observed, state intervention must be tempered: "so long as the child is part of a viable family, his own interests are merged with those of the other members. Only after the family fails in its function should the child's interests become a matter for State intrusion."[47] Thus, before a child's interest can be protected individually, the government must make a showing that the parent or parents are operating in a fashion that is not consistent with principles of family solidarity and privacy.[48]

Modern parents, under the neo-conservative standard, should exercise autonomy over the medical needs of their children. The crucial task is to locate the point at which parental choices so harm the child's welfare as to justify state intervention. It has been suggested that unless death is a likely consequence of the parental decision, there is no justification for governmental intrusion. An ameliorated position could state that only unreasonable parental actions warrant intervention. Introducing the standard of reasonableness gives wider significance and respect to parental autonomy. It is also a more realistic approach to decisional matters in this area.[49]

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[46]*Id.* at 467.

[47]J. GOLDSTEIN, A FREUD & A. SOLNIT, BEYOND THE BEST INTERESTS OF THE CHILD 130 (1973).

[48]*Supra* note 45.

[49]Smith, Quality of Life, Sanctity of Creation: Palliative or Apeotheosis?, 63 NEB. L. REV. 709 (1984).

The standard of reasonableness is always flexible and responsive to individual factual applications. This flexibility may be enhanced through interpretation and application of social policies emerging from each particular situation. Forces of reasonableness and social policy are balanced as justice or equity is sought in individual cases. The element of reasonable discretion must be accorded to the family in its unique position of knowledge. Determinations of the best interests of one family member must by necessity be based upon individual family beliefs in social, economic, and spiritual values. Each case must be considered individually, according to the context in which it arises.[50]

When a parent exceeds the standard of reasonable conduct regarding a newly born handicapped infant, decisive action should be taken by the state to protect the infant. An inherent sense of conscience, decency, or humaneness directs all loving parents. This assumes, of course, that the parents are themselves intelligent and contributing members of society. Obviously, in those cases where the parents are not competent members of society, the state must stand ready to pierce the familial veil of privacy where the parents are incapable of making mature, reasonable, and loving judgments regarding the medical treatment of their newborn. One could, for example, well imagine a case of a fourteen-year-old, drug dependent, and economically insecure young girl giving birth to a neonate. Due to her illness, modest economic circumstances, and lack of sophistication, such a mother may decide to try to prevent heroic measures from being undertaken on an infant determined "salvageable" by her attending physi-

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[50] *Id.* at 730.

cians. In this situation, the state would be justified – indeed, compelled – to act. Similarly, when confused religous purposes supposedly "compel" parents to withhold emergency blood transfusions or surgical interventions, the state must intervene to protect the infant.[51]

While familial self-determination cannot remain unfettered and unchallenged, intrusions by the state should only be tolerated when familial judgment – based upon consultation with wise and faithfully objective medical providers – "so exceeds the limits of reason" that the best interests of the incapacitated member are being flagrantly disregarded.[52] Stated conversely, a parent will be considered *prima facie* inadequate when he or she suffers a disabling mental illness, retardation, drug addiction, or major character defect. These criteria evince an objectivity that has been lacking in past judicial evaluations, which were based on the best interests of the child.[53]

A. THE CONTEMPORARY RIGHT OF PRIVACY ALLOWS FOR THE WITHHOLDING OF INFORMATION WHICH ONE DOES NOT CHOOSE TO RELEASE.

Mr. Justice Stevens, writing for a unanimous Court in *Whalen v. Roe,* 429 U.S. 589 (1977), endeavored to define the constitutional right of privacy by suggesting that it embraced not only a general "individual interest in avoiding

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[51] *Id.* at 731.

[52] McCormick, To Save or Let Die: The Dilemma of Modern Medicine, in HOW BRAVE A NEW WORLD at 378 (R. McCormick, ed. 1981). See generally, Smith, The Plight of The Genetically Handicapped Newborn: A Comparative Analysis, 9 HOLDSWORTH L. REV. 164 (1984).

[53] *Supra* note 49 at 731.

disclosure of personal matters" but a distinct "interest in independence in making certain kinds of important decisions."[54] In his Opinion, the Justice focuses not so much upon a general right of control of personal information as upon a very narrowly formulated right to withhold information.[55]

Over fifty-seven years ago, an equally erudite member of the Court, Mr. Justice Brandeis, stated – in reference to structuring a privacy right – that, "They [the makers of the Constitution] conferred, as against the government, the right to be left alone – the most comprehensive of rights and the right most valued by civilized men." *Olmstead v. United States,* 277 U.S. 438, 478 (1928).

Surely there is no more greater validation of a contemporary right of privacy as articulated by Mr. Justice Stevens than of the right of independence to withhold information from outside or third party interests in matters of familial health care. Decisions to pursue a particular modality of medical treatment or to decline treatment – absent a showing of child abuse or neglect when dealing with minors – are conducive to stabilizing a family environment. Section 504 of the Rehabilitation Act is an improper grant of authority for the regulations considered here that abridge the rights of familial autonomy and privacy by precluding the withholding of personal hospital records from federal governmental inspection and disclosure and furthermore invade the privacy of the doctor-patient relationship.

It is only when the states and the federal government are both willing and able to provide for adequate funding and

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[54]Whalen v. Roe, 429 U.S. 589, 599-600 (1977).

[55]L. TRIBE, AMERICAN CONSTITUTIONAL LAW 888 (1978).

support necessary to meet a standard of reasonable and proper care for severely handicapped children, that parental autonomy and privacy should be invaded and truly compromised (except to the extent that such exercises of privacy are subject presently to the state child abuse and neglect laws).[56]

CONCLUSION

Because of the foregoing reasons, the judgment of the court of appeals should be affirmed.

Respectfully submitted,

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Professor of Law
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September 30, 1985.

The *amicus curiae* wishes to acknowledge the assistance of Scott E. Squillace, a student at The Catholic University Law School.

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[56]Murray, The Final, Anticlimatic Rule on Baby Doe, HASTINGS CENTER REPORT 5 (June 1985). See also, Smith, Defective Newborns and Government Intermeddling, 25 MED. SCI. & LAW 44 (1985).

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No. 84-1529

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IN THE
Supreme Court of the United States
OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,
v.
AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF FOR AMICI CURIAE AMERICAN ACADEMY OF PEDIATRICS, AMERICAN PEDIATRIC SOCIETY, SOCIETY FOR PEDIATRIC RESEARCH, ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRMEN AND WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS

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November 4, 1985

BEST AVAILABLE COPY

QUESTION PRESENTED

Whether Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, permits the Department of Health and Human Services to regulate individual medical treatment decisions concerning critically ill infants or to regulate compliance with state reporting requirements, particularly in the absence of a record establishing that any improper activity by recipients of federal financial assistance—those covered by the Act—has occurred?

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IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

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BRIEF FOR AMICI CURIAE AMERICAN ACADEMY OF PEDIATRICS, AMERICAN PEDIATRIC SOCIETY, SOCIETY FOR PEDIATRIC RESEARCH, ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRMEN AND WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS

The American Academy of Pediatrics (the "Academy"), the American Pediatric Society, the Society for Pediatric Research, the Association of Medical School Pediatric Department Chairmen and the Western Association of Children's Hospitals submit this brief *amici curiae* in support of Respondents American Hospital Association, *et al.* and in opposition to the brief filed by Secretary Margaret M. Heckler ("the Secretary") of the Department of Health and Human Services ("HHS"). It is accompanied by written consents from Petitioner and Respondents.

INTEREST OF AMICI CURIAE

The Academy is a non-profit organization of more than 28,000 board-certified pediatricians who are the individuals most intimately involved in caring for seriously ill infants. Most of the Academy's members practice medicine in hospitals which would be affected by any decision of this Court concerning the application of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, to medical treatment of seriously ill infants. Further, the Academy's Committees on Children with Disabilities and Bioethics have coordinated educational programs on medical treatment decisions involving handicapped children, and have developed statements of bioethical principles for Academy adoption.

The Academy has also been actively involved in judicial and administrative proceedings considering the applicability of Section 504 to medical treatment decisions. The Academy was the lead plaintiff in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C.), *appeal dismissed*, No. 83-1407 (D.C. Cir. Aug. 4, 1983) ["*AAP v. Heckler*"], which invalidated an "interim final rule" promulgated under Section 504 concerning discrimination against handicapped infants. Second, the Academy commented on proposed rules regarding discrimination on the basis of handicap in medical treatment of infants. These rules, in revised form, are the regulations at issue in this case. 49 Fed. Reg. 1622 (Jan. 12, 1984) (J.A. 11-111).[1]

The American Pediatric Society, the Society for Pediatric Research and the Association of Medical School Pediatric Department Chairmen ("AMSPDC") represent the faculty and leadership of academic pediatric departments. Membership in the American Pediatric Society and the Society for Pediatric Research is conferred on the basis

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[1] J.A. —— refers to the Joint Appendix.

of scholarship, research, and contributions to pediatric education. AMSPDC members are responsible for operating the departments of pediatrics of virtually every major tertiary care center in which neonatal intensive care units are located. This case arises in large degree from the advances in pediatric care made by these physicians which make it possible to extend the lives of many disabled and premature infants.

The Western Association of Children's Hospitals ("WACH") is a non-profit organization of nine hospitals providing most of the tertiary and much of the primary care to seriously ill infants in the western portion of the United States. WACH was founded to promote recognition of the special needs and circumstances of children's hospitals in formulating public health care policy. Members of WACH commented on the proposed rules which, in revised form, are at issue in this case. Thus, WACH and its members have a direct interest in the case currently before this Court.

SUMMARY OF ARGUMENT

Petitioner invokes Section 504 to regulate individual medical treatment decisions involving critically ill infants. She entirely ignores the intrinsic complexity both of the medical conditions suffered by such infants and the medical decision making which accompanies them.

Petitioner suggests a paradigm case in which an infant possesses a static disability on the one hand, and a separate, easily treatable medical condition on the other. In fact, most infants subject to Petitioner's rule suffer from myriad, interrelated medical conditions, none of which can be characterized as static disabilities, and none of which are easily treatable. Moreover, the infants' medical conditions fluctuate continuously, so that the prognoses change from moment to moment. These factors render impossible any determination of "discrimination" under Section 504.

The very language of Section 504, and the case law interpreting it, demonstrate that the statute does not authorize federal intervention into treatment decisions for critically ill infants. Because there exists no "customary" standard of medical care applicable to all infants, it is impossible to determine whether a particular infant is "otherwise qualified" for a particular treatment. Second, the medical treatment decisions Petitioner seeks to regulate involve no "discrimination" by a federally-funded program or activity. Treatment decisions concerning critically ill infants are made by parents, who are not recipients of federal funds. Petitioner's convoluted attempt to involve hospitals in the decision-making process fails, since Section 504 does not require a recipient of *federal* funds to invoke the protections of a *state* child abuse program. Moreover, Petitioner cites no evidence that hospitals are ignoring their state reporting duties. Third, Petitioner's regulations constitute a burdensome and harmful intrusion into ongoing treatment, encouraging painful overtreatment and jeopardizing the quality of care received by the very infants Petitioner purports to protect.

Finally, the legislative history of Section 504 is devoid of any indication that Congress intended the statute to permit federal regulation of individual medical treatment decisions. Further, when Congress ultimately did address the issue of appropriate care for critically ill infants, it specifically decided that such issues should be left to the states.

ARGUMENT

I. PETITIONER'S CONCEPT OF "DISCRIMINATION" UNDER SECTION 504 FAILS TO ACCOUNT FOR THE COMPLEXITY OF MEDICAL CASES AND MEDICAL DECISION MAKING

As pediatricians involved in the daily care of seriously ill infants, *amici* are concerned that Petitioner has dramatically oversimplified the complex medical decision making which she intends to regulate under Section 504. Seriously ill infants typically suffer from complicated and interrelated medical conditions, which can change day to day, hour to hour. Medical decision making involves evaluation of complex and fluctuating factors, and the medical condition to be treated is often inseparable from the putative "handicap"; hence, the notion of "discrimination," which is the core of Section 504, has no application.

A. Seriously Ill Infants Do Not Present Simple, Straightforward Cases

Petitioner premises her Section 504 analysis on the case of the so-called "Baby Doe" infant in Bloomington, Indiana, a child born with several serious disabilities including Down's Syndrome and a tracheoesphageal fistula, an abnormal connection between the trachea and esophagus which prevents normal eating, but which is surgically correctable.[2] Petitioner argues that if a federally-assisted hospital withholds surgery to correct the intestinal problem solely on the basis of the child's anticipated mental retardation, when the hospital would perform the surgery for a "normal" child, the hospital has "discriminated"

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[2] Petitioner even misstates the facts of that case. At birth, the infant known as "Baby Doe" was preliminarily diagnosed as having a deformed heart. Although an autopsy on the child ultimately indicated no heart problems, at the time that the treatment decisions were being made, the potential heart defect was a serious consideration. *See* Pless, *The Story of Baby Doe*, 309 New Eng. J. Med. 664 (Sept. 15, 1983).

against the child "solely by reason of his handicap" in violation of Section 504. Brief for Petitioner ("Pet. Br.") at 15.

Petitioner's hypothetical application of Section 504 is thus premised on a simple, straightforward case in which one of the infant's conditions can be characterized as a "static" disability, and the other as a condition requiring medical treatment. In fact, the vast majority of critically ill infants in pediatric intensive care units who would come under Petitioner's regulations are not so afflicted, but suffer from multiple, interrelated medical conditions, to which the analysis of Petitioner's paradigm case is wholly inapplicable.

Premature infants constitute the largest percentage of infants in pediatric intensive care. These infants, particularly extremely premature infants (24-30 weeks' gestation and one to three pounds weight), may suffer from a multitude of interrelated problems, including: severe asphyxiation at birth; respiratory distress syndrome; compromised intestinal function; heart defects with congestive pulmonary failure; meningitis; septicemia; and immature organs, such as the brain and retina. *See, e.g.*, G. Avery, Neonatology: Pathophysiology and Management of the Newborn 241-55 (2d ed. 1981) ["Avery"]; Stahlman, *Newborn Intensive Care: Success or Failure?* 105 Pediatrics 162, 163-64 (1984).

Besides premature infants, other seriously ill infants suffer from such diverse and often interrelated disabilities as myelomeningocele (spina bifida); hydrocephalus (accumulated fluid in the cranial vault); anencephaly (absence of the cranial vault); and Trisomy 13 and Trisomy 18 (chromosomal defects resulting in a variety of medical disabilities). *See generally* Avery at 870-89, 944-46. For example, "Baby Jane Doe," the infant in *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984) [*"University Hospital"*], suffered from multiple birth defects, includ-

ing: microcephaly, an abnormally small head; hydrocephalus; inability to close her eyes or achieve sucking action; a malformed brain stem; upper extremity spasticity; and a thumb implanted in her fist. *Id.* at 146. In contrast to the hypothetical infant relied on by Petitioner, seriously ill infants do not present simple, straightforward treatment decisions which can be viewed as involving any sort of "discrimination."

B. Medical Decision Making Does Not Involve Isolated Treatment Decisions

In Petitioner's paradigm case, the pediatrician need only make one treatment decision: whether to perform surgery to correct an intestinal problem. *See* Pet. Br. at 15. Yet just as seriously ill infants do not suffer from static, isolated medical conditions, medical care of seriously ill infants rarely involves an isolated decision to treat one malady. Rather, pediatric care involves numerous treatment decisions which are typically based on an uncertain prognosis. Arras, *Toward an Ethic of Ambiguity*, 14 Hastings Center Report 25, 27 (Apr. 1984). The pediatrician must assess, often without reliable medical data, the likelihood of successful treatment, the risk of damage to the infant from the therapy, the effect on the child of protracted artificial life-support care, and the pain and suffering of continued treatment. Treatment may be life-saving, but the result of the therapy could cause other damage. For instance, use of mechanical ventilation with high levels of oxygen on a premature infant can cause blindness, a scarred trachea or severely damaged lungs. *See* D. Vidyasagar & A. P. Sarnaik, Neonatal and Pediatric Intensive Care 350 (1985); Avery at 13.[3]

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[3] Treatment of premature infants in particular requires an individualized assessment of all of the infants' complex and constantly changing medical conditions, including the immaturity of many organs:

The physician's ability to determine the child's prognosis is complicated by the child's constantly changing medical conditions—what the *University Hospital* court termed the "fluid context of medical treatment decisions." 729 F.2d at 156. The medical conditions of seriously ill infants can change minute to minute and hour to hour, often evading certain prognosis. *See* Avery at 13. The President's Commission for the Study of Ethical Problems in Medicine and Bioethical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (1983) ["President's Commission Report"] observed that "[f]requently . . . the prospect of long term survival and the quality of that survival remains unclear for days, weeks, and months, during which time the infants may have *an unpredictable and fluctuating course of advances and setbacks.*" *Id.* at 221 (emphasis added).[4]

Petitioner's argument that withholding medical treatment from a disabled infant "subject[s] . . . [the infant] . . . to discrimination" within the meaning of Section 504 thus grossly oversimplifies the medical decision-making process. The spectrum of medical conditions involved, and the numerous medical decisions necessary to respond to them, change continually. The result, as explained by the Second Circuit, is that:

> [w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory."

> The major therapeutic challenge in managing these very immature infants is not so much the specific treatment of disease entities as it is the control of the many pathophysiologic derangements resulting from prematurity itself.

Avery at 241.

[4] Indeed, in its brief in *University Hospital*, the government conceded this point, arguing there that it needed constant access to updated medical records because "[m]edical decision making is a dynamic process." Brief for the United States in *University Hospital* at 24.

University Hospital, 729 F.2d at 157. The treatment decision posited by the Secretary is a simple one; the reality is a far more complex one where differing medical conditions justify different treatment for individual infants. *See* Arras at 26. Thus, a decision which may in Petitioner's view constitute "discrimination" at one moment may become a bona fide medical judgment—concededly outside the scope of Section 504—the next. With the threat of federal intervention, adverse publicity, litigation, and possible loss of funding, the effect of the regulations would be to require treatment even where contraindicated, a gross intrusion into difficult and complex medical decisions.

II. REGULATING THE MEDICAL TREATMENT OF SERIOUSLY ILL INFANTS EXCEEDS THE SCOPE OF SECTION 504

Section 504 is generally designed to assure meaningful access by otherwise qualified handicapped individuals to federally-funded programs. *See Alexander v. Choate*, 105 S. Ct. 712, 721 (1985). The language of the statute and the case law interpreting it uniformly establish that it has a limited scope. First, it only prohibits discrimination against "otherwise qualified" handicapped individuals. Second, Section 504 only prohibits discrimination under a program or activity receiving federal financial assistance. Third, the provision cannot be interpreted to impose unwarranted affirmative action burdens on providers. Petitioner's expansive reading of Section 504 ignores each of these limitations.

A. A Seriously Ill Infant Is Not An "Otherwise Qualified" Handicapped Individual

This Court, in *Southeastern Community College v. Davis*, 422 U.S. 397, 406 (1979), held that an "otherwise qualified" individual within the meaning of Section 504 is "one who is able to meet all of the program's requirements in spite of his handicap." In the context of health

services, Petitioner argues that if a hospital offers a particular treatment that the infant requires, then the infant is "otherwise qualified," as long as such treatment would be "medically beneficial." Pet. Br. at 22-24. Petitioner suggests that a determination of medical benefit is easy because it is "the sort of judgment that health care professionals are accustomed to making on behalf of all of their patients." Pet. Br. at 25-26. Petitioner's interpretation of the "otherwise qualified" statutory requirement, however, completely ignores the complexity of such medical judgments.

First, "medical benefit" has no intrinsic meaning. Whether a particular child would "medically benefit" from a particular course of treatment depends on that child's prognosis, and is therefore inherently individualized—hardly a "bona fide standard" of "general applicability" which Petitioner admits is the relevant determination of "otherwise qualified" under Section 504. *See* Pet. Br. at 22. As Judge Gesell stressed in *AAP v. Heckler*, "*there is no customary standard of care* for the treatment of severely defective infants." 561 F. Supp. at 400 (emphasis in original).

Second, as noted above, a seriously ill infant's medical conditions are constantly changing. Given the "fluid" nature of these medical conditions, during one hour an infant could be deemed "otherwise qualified" because treatment would be "medically beneficial," but the next hour fail Petitioner's "otherwise qualified" test because treatment would be futile or merely temporarily prolong the act of dying. *See* 45 C.F.R. Pt. 84, App. C ¶ (a) (2) (J.A. 122).

Petitioner is unable to respond to the inherent difficulty of determining whether a seriously ill infant is "otherwise qualified" given the reality of constantly changing medical conditions. Petitioner argues that federally-funded educational or physical rehabilitation pro-

grams, which are clearly covered by Section 504, also must account for fluctuations and developments in a child's physical and mental condition. Pet. Br. at 26 n.15. The two situations are easily distinguishable. First, while the child's mental or physical conditions may fluctuate in an educational setting, the fluctuations are not life-threatening, and do not change on a minute-by-minute basis. More importantly, decisions in the educational setting are made by schools and teachers, and *not*, as under Petitioner's final rules, by the federal government. Generally, the role of the federal government has been to ensure that schools have programs available which will respond to the individual needs of handicapped students. There can be no question that the health care services available for the treatment of seriously ill infants satisfy that test. The Secretary wishes to go much further in the hospital context than making sure services are available; rather, she would intrude into individual treatment decisions—a role beyond the scope of Section 504.

B. Medical Treatment Decisions Do Not Involve "Discrimination" By A Federally-Assisted Program or Activity

Petitioner also fails to make out a case of discrimination. Section 504 by its plain language only prohibits discrimination against handicapped individuals "under a program or activity receiving federal financial assistance." Petitioner concedes she cannot regulate *parents'* decisions concerning treatment for their children, because parents are not recipients of federal financial assistance. 45 C.F.R. Pt. 84, App. C ¶ (a)(4) (J.A. 122). She has retreated, therefore, to postulating a case whereby a federally assisted *hospital* potentially discriminates against critically ill infants. Petitioner argues that if a hospital "refused to furnish treatment to a handicapped infant, even though it would furnish the treatment to a nonhandicapped child, the infant has, 'solely by reason of his handicap,' been 'denied the bene-

fits of' and been 'subjected to discrimination under' the federally assisted program." Pet. Br. at 13. Alternatively, Petitioner argues that, where the parents have withheld their consent to treatment, the hospital's refusal to notify the state child protective services ("CPS") agency or to petition a state court for an order directing treatment, subjects the handicapped infant to discrimination under the hospital's federally-assisted program if the hospital would have undertaken such efforts for other children in similar circumstances. *Id.*

Petitioner's argument again is divorced from medical reality. Petitioner can point to no case—because no case exists—where a *hospital* has refused to treat a handicapped child against the wishes of the parents and the treating physician. Hospitals are always prepared to render services when the parents, in consultation with the treating physician, determine that treatment is medically indicated. In *University Hospital*, for example, the hospital was at all times willing to perform the treatment at issue, but lacked the legal authority to do so without parental consent. *University Hospital*, 729 F.2d at 148. If requiring hospitals to make treatment available is the focus of Petitioner's application of Section 504, she has no basis for imposing any regulation, for the "problem" simply does not exist.

Recognizing that she cannot directly regulate parental treatment decisions, and identifying no case where a hospital refused to treat a disabled infant against the wishes of the infant's parents, and, finally, conceding that hospitals lack the legal authority under state law to treat an infant *sua sponte* without parental consent, Petitioner is forced to make a different argument: that a hospital would violate Section 504 not by any act or omission in treatment but instead if it refused to execute its duty under state law to report to the state CPS agency known or suspected cases of unlawful medical neglect. Pet. Br. at 13; *see* 45 C.F.R. § 84.55(c) and 45 C.F.R.

Pt. 84, App. C, ¶ (a)(4) (J.A. 122). There are several problems with this tortured analysis.

First, the legislative history of Section 504 is devoid of any indication that Congress intended a *federal* statute to enforce a recipient's *state* law duties. *See infra*, pp. 18-25. Section 504 was intended to require recipients of federal funds to provide access to the programs and activities for which the recipient receives such funds. *Alexander v. Choate*, 105 S. Ct. at 721. Here, Petitioner construes Section 504 to require the hospital to provide access to a "program" wholly beyond its federally-funded program of furnishing health care—state administrative and judicial proceedings.[5]

In *Bell v. Board of Education, Akron Public Schools*, 683 F.2d 963, 968 (6th Cir. 1982), a case arising under Title VI of the Civil Rights Act in the context of school desegregation, the Sixth Circuit held that where there had been discriminatory practices by federal and state housing authorities, it would place "too heavy a burden" on the school board to require the board to go beyond the scope of its program (education) to remedy discrimination by another program (housing). *See also Goldsboro Board of Education v. Wayne County Board of Education*, 745 F.2d 324, 328 (4th Cir. 1984) ("[a]n independent school district which has not caused segregation in a neighboring independent district has no duty to rectify a racial imbalance in the other district"). Similarly, Section 504 prohibits discrimination and requires remedial action only within the hospital's own program, i.e., furnishing health care.

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[5] This Court has recognized that simply because an entity receives federal funds does not mean that every action taken by that entity is subject to Section 504. Rather, the antidiscrimination prohibition only applies to the "program or activity" receiving federal funds. *Grove City College v. Bell*, 104 S. Ct. 1211, 1220-22 (1984). Petitioner does not suggest, and certainly has no administrative record to support any contention, that federal funds are provided to hospitals to support their reporting duties.

Second, Petitioner cites no evidence that hospitals are ignoring their state reporting duties. Even in Petitioner's paradigm case of Bloomington "Baby Doe," when the infant's parents decided to withhold surgery, the attorney for the hospital promptly notified the county circuit court to arrange for a hearing. *In re Infant Doe*, No. GU 8204-004A, slip op. at 2 (Monroe County Cir., Apr. 12, 1982), *writ of mandamus dismissed sub nom. State ex rel. Infant Doe v. Baker*, No. 482 S 140 (Ind. May 27, 1982), *cert. denied*, 104 S. Ct. 394 (1983). *See also* Holder, *Parents, Courts and Refusal of Treatment*, 103 Pediatrics 515, 516 (Oct. 1983). In Petitioner's preamble to the final rule, she describes numerous instances where hospitals, on their own initiative, notified the state CPS agency pursuant to state law, but she was unable to point to even one case where a hospital failed to invoke such procedures. *See* 49 Fed. Reg. 1646-49 (J.A. 96-106). The "problem" Petitioner identifies simply does not exist.

Third, and most important, the need to ensure proper reporting of medical neglect was directly addressed in the Child Abuse Amendments of 1984. *See infra* pp. 19-22. Congress' enactment of specific legislation building on existing state procedures for dealing with child abuse and neglect indicates its determination that such procedures already protect child welfare. Petitioner's interpretation of Section 504 to permit intrusive federal investigation and enforcement of this state law function is thus unnecessary, duplicative and potentially disruptive to furnishing pediatric care.

C. The Regulations Unnecessarily Intrude Into Medical Treatment Decisions And Would Improperly Require Affirmative Action By Hospitals

This Court also recognized in *Davis* that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds." 442 U.S. at 411. In *Davis*, a licensed

practical nurse contended that her denial of admission to a college nursing program on the basis of her hearing disability violated Section 504. As part of her argument, she asserted that regulations implementing Section 504 required that the nursing program be modified to accommodate her, to which this Court replied:

> If these regulations were to require substantial adjustments in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals, they would do more than clarify the meaning of § 504. Instead, they would constitute an unauthorized extension of the obligations imposed by that statute.

Id. at 410. This Court thus distinguished the provision of equal opportunity from affirmative action, stating that "[t]he language and structure of the Rehabilitation Act of 1973 reflect a recognition by Congress of the *distinction between the evenhanded treatment* of qualified handicapped persons *and affirmative efforts to overcome the disabilities* caused by handicaps." *Id.* (emphasis added). This Court found that Section 504 does not require institutions to take substantive steps outside of their ordinary programs to eliminate or overcome handicaps. *Id.* at 413. *See also Doe v. New York University*, 666 F.2d 761, 775 (2d Cir. 1981) (school "not obligated by the Act to alter, dilute or bend [its admission standards] to admit the handicapped applicant").

This Court has also recognized that Section 504 must be kept "within manageable bounds." *Alexander v. Choate*, 105 S. Ct. at 720-21 n.20. Further, it cannot serve as a basis for a "burdensome . . . mandate" on federally-assisted activities or programs. *American Public Transit Association v. Lewis*, 655 F.2d 1272, 1278 (D.C. Cir. 1981). Petitioner's rules constitute exactly the kind of burdensome and disruptive measures against which these decisions cautioned. Under Petitioner's rules, nonmedical teams of HHS employees, designated by HHS as

"Baby Doe Squads," are granted expedited access to investigate reports of suspected discriminatory treatment of infants, including anonymous reports to HHS' "hotline." *See* 45 C.F.R. § 84.55. In *AAP v. Heckler*, Judge Gesell concluded that the intrusion of these "Baby Doe Squads" imposed unwarranted burdens on hospitals, and endangered the health of the infant:

> [A]ny anonymous tipster, for whatever personal motive, can trigger an investigation involving immediate inspection of hospital records and facilities and interviewing of involved families and medical personnel. In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of "Baby Doe" squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

AAP v. Heckler, 561 F. Supp. at 399 (footnote omitted).

Judge Gesell's conclusion that the quality of care suffers from such intrusive federal regulations is well documented. In one instance at Vanderbilt University Hospital, a "hotline" call alleged—without basis—that the hospital was not providing proper care to ten children. The call resulted in a time-consuming and disruptive Baby Doe squad investigation that took 39 hours from doctors and nurses who would have otherwise spent their time caring for patients.[6] Moreover, the investigation disrupted the medical care given the ten patients involved. One child's surgery had to be postponed and another remained in the pediatric intensive care unit

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[6] Affidavit of Norman B. Urmy, Director, Vanderbilt University Hospital, ¶ 10 (J.A. 185).

longer than necessary because the HHS investigators held necessary medical records.[7]

In another instance, an anonymous "hotline" call was triggered by a newspaper article stating that conjoined twins at Strong Memorial Hospital at the University of Rochester might not survive. The call led to a disorganized and time-consuming investigation by a Baby Doe squad.[8] The investigators argued among themselves as to which HHS office was entitled to the medical information, and then flew in a Virginia neonatologist without having even obtained the parents' consent to examine the children.[9] Although HHS investigators later confirmed that the care provided was exemplary, they refused at the time to issue a public statement retracting their allegations that would counter the trauma experienced by parents and the community from newspaper reports of the incident. The unwarranted investigation created fears in parents of other critically ill children as to the adequacy of the hospital's care, prompting one family to have its seriously ill child discharged—based on the unfounded fear that the hospital was intentionally harming children—before treatment was complete.[10] Clearly Congress did not intend Section 504 to authorize intervention which would harm the very individuals it is purporting to protect from discrimination.

In *AAP v. Heckler*, Judge Gesell observed in invalidating Petitioner's interim rule that "many highly relevant factors central to any application of Section 504 to medi-

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[7] *Id.* ¶ 11 (J.A. 185).

[8] Affidavit of Paul M. Rosenberg, Associate Director, Fiscal & Administrative Services, Strong Memorial Hospital, University of Rochester, ¶ 16 (J.A. 178).

[9] ¶¶ 8-13 (J.A. 179-80).

[10] ¶ 16 (J.A. 181).

cal care of the newborn infants were not considered prior to promulgation of the challenged rule." 561 F. Supp. at 399. Despite renewed rulemaking proceedings and slightly modified final rules, Petitioner to date has still failed fully to consider or address the serious implications of her rules, including the disruption, delay, and complications of federal investigators intruding in ongoing treatment of seriously ill infants, and the risk of painful overtreatment.[11] The regulations promulgated under Section 504 require just the sort of affirmative burden and disruption to federally-assisted programs which this Court has repeatedly found to be beyond Congress' intention in adopting Section 504.

III. CONGRESS DID NOT INTEND THAT SECTION 504 SERVE AS THE BASIS FOR FEDERAL INTERVENTION IN INDIVIDUAL MEDICAL TREATMENT DECISIONS

The expansive reading of Section 504 urged by Petitioner is also unsupported by the statute's legislative history and Congress' subsequent legislation concerning treatment decisions involving seriously ill infants. Equally unpersuasive is Petitioner's attempt to find congressional support for her interpretation by analogy to other statutes. Petitioner cannot cite any evidence that Congress intended Section 504 to authorize intervention in the critical care nursery in the manner contemplated by her rules.

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[11] *See* Affidavit of Hubert A. Ritter, M.D., obstetrician-gynecologist and clinical professor at St. Louis University School of Medicine, submitted by the American Medical Association in the Joint Appendix of American Hospital Association v. Heckler, Nos. 84-6211, 84-6213 (2d Cir. 1984) at 155 ¶ 10 (regulations encourage physicians to recommend over treatment in particular cases to avoid investigations as to whether the failure to offer treatment constitutes "discrimination," even though such treatment may not be in the best interest of the child).

A. The Child Abuse Amendments Represent Congress' Belief That Medical Treatment Decisions Regarding Seriously Ill Infants Are Best Addressed Under Existing State Mechanisms

The only occasion on which Congress has specifically addressed the subject of medical care of seriously ill infants is in the Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* ["Amendments"]. The Amendments demonstrate Congress' belief that medical treatment decisions regarding seriously ill infants should be dealt with under existing state administrative and judicial procedures. Under the Amendments, to receive grants for its CPS system, a state must establish procedures for: (1) consultation with designated individuals in hospitals; (2) notification of cases of suspected medical neglect (including instances of withholding of medically-indicated treatment from disabled infants with life-threatening conditions); and (3) legal remedies, under state law, for the CPS agency to prevent the withholding of medically-indicated treatment frob disabled infants with life-threatening conditions. Section 122 of the Amendments, 98 Stat. 1752-53 (amending 42 U.S.C. § 5103(b)(2)(K)).[12] Petitioner admits that these proce-

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[12] The Secretary has issued final regulations implementing the Amendments. 50 Fed. Reg. 14878 (Apr. 15, 1985). Pursuant to the Amendments, the Secretary also issued Model Guidelines for Health Care Providers to Establish Infant Care Review Committees ("ICRCs"). 50 Fed. Reg. 14893 (Apr. 15, 1985). *Amici* strongly support the establishment of review committees and bioethics committees to provide consultation and to ensure that sensitive treatment decisions are made in a reasoned, informed and caring manner. The President's Commission Report also recommended intra-institutional ethics committees to review treatment decisions involving seriously ill infants. President's Commission Report at 226-27 (J.A. 190-91). According to the Academy's 1984 survey of ICRCs attached as Appendix II to Comments of the American Academy of Pediatrics (Feb. 8, 1985) on Proposed Rule Regarding Child Abuse and Neglect Prevention and Treatment Program and Interim Model Guidelines for Infant Care Review Committees, 49 Fed. Reg.

dures are similar to regulations promulgated under Section 504, the authority for which is at issue here. Pet. Br. at 8 n.5.

The Amendments must be viewed in the context of what Petitioner has conceded was an "extraordinary effort" to enact legislation in this most sensitive area. 50 Fed. Reg. at 14879. In *AAP v. Heckler*, Judge Gesell struck down the first "interim final rule," finding that HHS lacked a rational factual basis for the rule and that the agency had failed to follow required notice and comment procedures. 561 F. Supp. at 403. Judge Gesell cited numerous shortcomings in the rule, including the disruptive effect of HHS' enforcement procedures in caring for disabled newborns. *Id.* at 399. He also suggested that this issue "be clarified by further congressional action." *Id.* at 402. HHS then issued a new proposed rule and solicited public comment. While HHS was in the process of preparing its final rule, the case of "Baby Jane Doe" again raised the question of HHS' authority under Section 504 to intervene in medical treatment decisions, which led, after extensive proceedings, to the *University Hospital* decision.

Thus, in the fall of 1984 when Congress adopted the Amendments, it was well aware of the serious legal and policy questions raised by these cases regarding federal regulation of medical treatment decisions.[13] Since the

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48160 and 49 Fed. Reg. 48170 (Dec. 10, 1984), many hospitals already have an ICRC or bioethics committee, and the number of such committees is growing rapidly. Thus, the majority of hospitals which would be subject to Petitioner's rules already have a mechanism, in conjunction with the state CPS system, to review cases of seriously compromised infants and to ensure that when treatment is medically indicated, the infant will receive appropriate care.

[13] *See, e.g.*, S. Rep. No. 246, 98th Cong. 2d Sess. 6-8 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2918, 2922-25; 130 Cong. Rec. S8956 (daily ed. June 29, 1984) (remarks of Sen. Nickles). The Senate Report noted that "[t]he highly publicized

same congressional committees have jurisdiction over both Section 504 and the child abuse and neglect grant program, Congress could easily have overruled *University Hospital* by expressly amending Section 504 to include coverage of medical treatment decisions concerning disabled infants. Instead, Congress chose to leave such issues to the states, to carry out their traditional role in the area of child abuse and neglect.

As recognized by this Court, the "failure of Congress to alter [a statute] after it had been judicially construed, and the enactment by Congress of legislation which implicitly recognizes the judicial construction as effective, is persuasive of legislative recognition that the judicial construction is the correct one." *Apex Hosiery Co. v. Leader*, 310 U.S. 469, 488 (1940); *see also Blue Chip Stamps v. Manor Drug Stores*, 421 U.S. 723, 732-33 (1975); *Lewis v. United States*, 663 F.2d 889, 891 (9th Cir. 1981), *cert. denied*, 457 U.S. 1133 (1982). Moreover, the same congressional committee that originally enacted Section 504 subsequently defined the scope of the federal role in medical treatment decisions concerning seriously ill infants; as such, that interpretation can be considered "virtually conclusive" as to Congress' prior intended meaning. *Sioux Tribe of Indians v. United States*, 316 U.S. 317, 329 (1942); *see also Socony Mobil Oil Co. v. United States*, 287 F.2d 910, 914 (Ct. Cl. 1961); *accord Abell v. United States*, 518 F.2d 1369 (Ct. Cl. 1975), *cert. denied*, 429 U.S. 817 (1976). Given Congress' clear decision to enact specific legislation governing medical treatment decisions involving disabled infants, Petitioner's contention that there is "firm support" for her interpretation of Section 504 "at every stage of

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recent cases have catapulted the issue of withholding treatment from seriously ill infants into the public arena. . . ." S. Rep. No. 246, 98th Cong. 2d Sess. 6 (1984), *reprinted in* 1984 U.S. Code Cong. & Ad. News 2923.

the evolution" of legislation in this area is mere hyperbole.[14]

B. Congress' Goal In Enacting Section 504 Was To Increase Access To Federally Funded Programs, Not To Intrude Into Individual Medical Treatment Decisions

This Court has recognized that "language as broad as that of § 504 cannot be read in isolation from its history and purposes." *Consolidated Rail Corp. v. Darrone*, 104 S. Ct. 1248, 1254 n.13 (1984). The legislative history of Section 504 demonstrates that Congress did not contemplate federal regulation of medical treatment decisions.

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[14] In the Amendments, Congress adopted a "policy of neutrality" regarding the application of Section 504 to medical treatment decisions involving seriously ill infants. 130 Cong. Rec. S12392 (daily ed. Sept. 28, 1984) (letter from sponsors Senators Hatch, Denton, Nickles, Kassebaum, Dodd and Cranston). The Amendments state that nothing in the statute "is intended to affect any right or protection under Section 504 of the Rehabilitation Act of 1973," Section 127(a), 98 Stat. 1754. Nevertheless, in addressing the issue of medical care of disabled infants, Congress made a specific decision to use the state CPS system rather than authorizing federal intervention.

Moreover, Congress was so sensitive to the painstaking process which led to the enactment of the Amendments that the Senate sponsors prepared a Joint Explanatory Statement describing the statute. In this statement, the sponsors identify the statement as the "definitive legislative history" of the provisions and expressly state:

> Any remarks of individual Senators, including the principal sponsors, on this legislation express only their personal views and do not, therefore, constitute authoritative interpretation or explanation of the measure.

130 Cong. Rec. S8953 (daily ed. June 29, 1984). Accordingly, Petitioner's references to passages in committee reports and debates endorsing the application of Section 504 to treatment decisions of seriously ill infants (Pet. Br. at 45 n.36) do not represent congressional intent and should not be considered by this Court.

In drafting Section 504, Congress initially was concerned with discrimination against handicapped individuals only in terms of employment. *See, e.g.*, 119 Cong. Rec. 24,587 (daily ed. July 18, 1973) (remarks of Sen. Taft on S. 1875, 93d Cong., 1st Sess. 1973)).[15] Later, this goal was expanded in an effort to remove barriers to access in education, transportation, and social services.[16] Contrary to Petitioner's assertion (Pet. Br. at 35-39), that expansion in no way evidences an intent to authorize federal regulation of medical treatment decisions. To the extent that Congress even contemplated "health services" as being subject to Section 504, it did so only in the sense of requiring providers to make such services equally available to all persons able to meet a particular program's requirements despite their disability, a far different situation than the regulation of individual medical care contemplated here. *See* S. Rep. No. 1297, 93d Cong., 2d Sess. 38, *reprinted in* 1974 U.S. Code Cong. & Ad. News 6373, 6388-89. The only specific reference in the legislative history to medicine or health services is in the context of *access* (as opposed to individual treatment decisions) to nursing home services:

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[15] Accordingly, Congress originally defined the phrase "handicapped individual" in terms of employment:

> The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services. . . .

Section 7(6), Pub. L. No. 93-112, 87 Stat. 355.

[16] As part of the Rehabilitation Act Amendments of 1974 (Pub. L. No. 93-516, § 111(a), 88 Stat. 1619), Congress expanded the definition to encompass "impairments to major life activities." Under the 1974 amendments, a "handicapped individual" is:

> any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment.

> Examples of handicapped individuals who may suffer discrimination in the receipt of Federally-assisted services but who may have been unintentionally excluded from the protection of Section 504 by the references to enhanced employability in section 7(6) are as follows:
>
> * * * *
>
> admission to Federally-assisted nursing homes on the basis of their handicap. . . .

Id.

In sum, no part of the language or legislative history of the Rehabilitation Act of 1973 indicates a congressional concern with individual medical decisions, much less physician and parental decisions concerning complex medical treatment for critically ill infants.[17] In addressing the scope of Section 504 in the context of disparate-impact discrimination, this Court expressly noted that if Congress had intended the statute to reach all such claims, "we would expect some indication of that purpose in the statute or its legislative history. Yet there is nothing to suggest that such was Congress' purpose." *Alexander v. Choate*, 105 S. Ct. at 720. The same is true here. Had Congress intended Section 504 to reach medical decisions, some indication of this intent would be evident in the legislative history. As noted by the Second Circuit, "the failure of congress to focus on treatment decisions involving defective newborn infants strikes a

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[17] In enacting Title XVIII of the Social Security Act (42 U.S.C. §§ 1395 *et seq.*), commonly known as the Medicare program, Congress specifically prohibited "any federal officer or employee" from exercising "any supervision or control over the practice of medicine or the manner in which medical services are provided. . . ." 42 U.S.C. § 1395. Given this broad prohibition in a statute dealing directly with the provision of health care, it is implausible that Congress would have intended intrusive federal interference in treatment decisions in a statute of general applicability.

telling blow to the government's position." *University Hospital*, 729 F.2d at 160.[18]

C. Petitioner's Analogy To Title VI Is Inapposite

Petitioner asserts that by patterning Section 504 after Title VI of the Civil Rights Act, Pub. L. No. 88-352, 78 Stat. 252 (codified at 42 U.S.C. §§ 2000d *et seq.*), Congress intended that Section 504's prohibition against discrimination because of handicap be construed as broadly as Title VI's prohibition against racial discrimination. Pet. Br. at 30-31. Yet the very decisions of this Court cited by Petitioner to support this assertion demonstrate that Section 504 does not incorporate the sweeping prohibition of discrimination on the basis of handicap that Title VI mandates for discrimination on the basis of race. *Alexander v. Choate*, 105 S. Ct. at 717 ("there are reasons to pause before too quickly extending [case law interpreting Title VI] to § 504"); *see also Consolidated Rail*, 104 S. Ct. at 1254 n.13. Indeed, this Court's decisions have recognized that Section 504 does not mandate a total ban on distinctions in federally-funded programs between individuals on the basis of handicap. *See Davis*, 442 U.S. 397; *cf. Community Television of Southern California v. Gottfried*, 459 U.S. 498 (1983) (holding that Section 504 does not require the Federal Communications Commission to alter its standard for reviewing public television license renewal applications to include consideration of the needs of the hearing-impaired).

Moreover, Petitioner proposes an overly simplistic analogy between Title VI and Section 504. Petitioner

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[18] In *AAP v. Heckler*, Judge Gesell also noted that while Section 504 was open to broad interpretation, "no congressional committee or member of the House or Senate *ever even suggested* that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life." 561 F. Supp. at 401 (emphasis added).

argues that Title VI prohibits a federally-assisted hospital from refusing surgery on an infant solely because of his race, and, hence, that Section 504 prohibits the hospital from refusing surgery solely because of the infant's handicap. Pet. Br. at 31, 35-36. This argument ignores the essential differences between race and handicap in the context of medical decision making. First, whereas race is a single factor wholly unrelated to medical treatment, the "handicaps" to which Petitioner refers are multiple medical conditions integrally related to the medical conditions to be treated and are often an essential consideration in the decision as to what type of medical care is appropriate. *See University Hospital*, 729 F.2d at 156.

Second, whereas race is fixed and immutable, an infant's medical conditions are constantly changing. *See supra*, pp. 8-10. Thus, while a decision to deny treatment to a black infant on the basis of race will always be discrimination under Title VI, no such finding of discrimination is possible in the context of medical treatment of a critically ill infant since different treatment decisions must be geared to particular infants and their changing medical conditions. Thus, Petitioner's analogy to Title VI is inapposite.

D. Petitioner's Analogy To A Specific Statute Prohibiting Discrimination In Medical Treatment On The Basis Of Alcohol Abuse Is Inapposite

Petitioner also fails to show support for her Section 504 interpretation by analogy to a specific statute prohibiting federally-funded medical facilities from discriminating in admissions or treatment against alcoholics or alcohol abusers because of their alcoholism (42 U.S.C. § 290dd-2(a)). Pet. Br. at 37-39. Alcohol and drug abuse are fundamentally different types of "handicaps" than the complex set of medical conditions affecting a

seriously ill infant. Alcohol and drug abuse, although disabling in effect, by definition develop from external factors in an individual's environment. Moreover, drug and alcohol abuse are treatable. A disabled infant's "handicap," on the other hand, consists of congenital and acquired impairments, which often are not treatable. To equate alcohol and drug abusers with seriously ill infants simply lacks any rational basis.

More importantly, Petitioner ignores the fundamental fact that Congress enacted a specific statute to address medical treatment decisions involving alcoholics and alcohol abusers, and, by implication, deliberately decided against creation of a specific statute for seriously ill infants. Petitioner apparently suggests that, since Congress has expressly prohibited federally-funded facilities from discriminating against alcoholics and alcohol abusers in furnishing medical treatment, it intended that Section 504 apply to all medical treatment decisions. Pet. Br. at 37-39. That analysis ignores a basic rule of statutory construction that where a statute specifically addresses one form of conduct and the persons to which it refers, all omissions must be construed as exclusions. *See Duke v. University of Texas at El Paso*, 663 F.2d 522, 526 (5th Cir. 1981), *cert. denied*, 105 S. Ct. 386 (1984) ("the absence of a specific prohibition on the discriminatory acts alleged . . . supports an inference that the legislature did not intend to outlaw other acts of employment discrimination by submerging an implied ban elsewhere in the statute"); *see generally* Sutherland, Statutory Construction § 47.23 (4th ed. 1984). Petitioner concedes that Congress enacted "*special* statutory provisions prohibiting discrimination against alcoholics and drug abusers. . . ." Pet. Br. at 41-42 (emphasis added). Since Congress chose specifically to regulate medical treatment involving alcohol abusers but not other patients, it must be presumed that Congress did not intend, in enacting

Section 504, to intrude into other medical treatment decisions.[19]

CONCLUSION

For the reasons set forth herein, the decision of the court below should be affirmed.

Respectfully submitted,

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November 4, 1985

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[19] Indeed, had Congress intended Section 504 to encompass all medical treatment decisions, it would have had no reason in 1974 to extend to all hospitals receiving federal financial assistance the prohibition against discrimination on the basis of alcoholism (Pub. L. No. 93-282, § 121(a), 88 Stat. 130 (codified at 42 U.S.C. § 4581(a) (1970 and Supp. IV 1974)), or, in 1976, further to amend the provision to apply to federally-assisted outpatient facilities (Pub. L. No. 94-371, § 11(a), 90 Stat. 1041 (codified at 42 U.S.C. § 290dd-2(a))). Congress cannot be presumed to have intended to enact redundant and unnecessary statutory amendments. *Uptagrafft v. United States*, 315 F.2d 200, 204 (4th Cir.), *cert. denied*, 375 U.S. 818 (1963).

No. 84-1529

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IN THE

Supreme Court of the United States

October Term, 1985

MARGARET M. HECKLER,
SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

against

AMERICAN HOSPITAL ASSOCIATION, ET AL.,
Respondents.

On Writ of Certiorari to the United States Court of Appeals For the Second Circuit

BRIEF FOR AMICUS CURIAE, THE STATE UNIVERSITY OF NEW YORK

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On Writ of Certiorari to the United States Court of Appeals For the Second Circuit

BRIEF FOR AMICUS CURIAE, THE STATE UNIVERSITY OF NEW YORK

Interest of the Amicus

The State University of New York is a legislatively created body, governed by a Board of Trustees, which operates and administers university centers, four year colleges, two year community centers, two year community colleges and other institutions of higher education. See, generally, New York Education Law § 350 *et seq.* Included within the University's system are three major teaching hospitals, two of which contain neonatal units. As an agency of state government, the University is represented here by the Attorney General of New York.

The general interest of the State University arises from its operation of the hospitals within its system, and particularly their neonatal units, where seriously impaired newborn infants have been and continue to be patients and where other hospitals often refer such infants for specialized care. New York regulates, through comprehensive legislation, the conduct of physicians and other health care providers. (N.Y. Public Health Law § 2800 *et seq.* [McKinneys 1977]). Amicus' concern and interest in the issues presented to this Court became direct and immediate in October, 1983, when a newborn infant suffering from multiple and serious congenital birth defects was admitted to the neonatal unit of University Hospital at Stony Brook. That admission resulted in extensive litigation in both the state and federal courts, with the hospital being represented throughout by the Attorney General. The litigation culminated in the decision of the United States Court of Appeals for the Second Circuit in *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984). That decision was the basis for the Court of Appeals' decision currently under review.

In the State University's view, the decision of the Second Circuit was a correct reading of the intent of Congress and should be sustained. Adopting the position of the federal government would not only sanction an obvious attempt at agency legislation but would be seriously deleterious to the interests of hospitals, doctors, and patients and their families throughout the country.

Accordingly, this brief will demonstrate the harmful effect of the federal government's intrusion into medical

treatment decisions made by the parents of a severely handicapped child in consultation with the treating physician and the effects the challenged regulation would have on the effective provision of health care in the neonatal unit at the University Hospital and other similar health care facilities.

ARGUMENT

Section 504 of the Rehabilitation Act does not authorize federal intervention in medical treatment decisions concerning severely handicapped newborns which are made by parents in consultation with their physicians.

The Secretary of the Department of Health and Human Services ("HHS") argues that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 ("Section 504") permits her to review—and even second-guess—medical treatment decisions of parents of severely handicapped children made in consultation with their treating physicians. The Secretary's simplistic approach to the treatment of impaired infants and her expansive interpretation of Section 504, however, are undermined by the facts of the University Hospital case, the statute itself and its legislative history, and the agency's previous interpretation of Section 504. Moreover, because the regulations implicate constitutionally protected privacy rights, the "exercise of particular care", *United States* v. *University Hospital*, 729 F.2d at 150, is required in determining whether the regulations fall within the Secretary's statutory authority.

A. The Baby Jane Doe Case: *United States v. University Hospital.*

Purportedly acting under the authority of Section 504, the federal government on October 22, 1983 attempted to interfere in the medical treatment being provided to an infant, Baby Jane Doe, at University Hospital's neonatal intensive care unit. The government demanded that the hospital give it access to the infant's medical records. Its asserted purpose was to determine, after a review of the medical records, whether Baby Jane Doe, who was suffering from many serious congenital birth defects, was being "discriminated against by reason of the decision not to provide dual corrective surgeries to the child". (Complaint, ¶¶ 11 and 14).[1] The legal predicate for its request was its view that the hospital's failure to perform surgery on the baby could be discriminatory under the Rehabilitation Act.

1. The Facts.

On October 11, 1983, Baby Jane Doe was born in St. Charles Hospital, Port Jefferson, New York (E. 35). That evening, she was transferred to University Hospital for evaluation of her condition and for possible surgery (E. 36, 41). The attending neurologist examined the child upon her arrival and found that she was suffering from multiple serious congenital birth defects (E. 36-40, 58), specifically,

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1. The complaint was included in the appendix which was filed with the Court of Appeals. The appendix consisted of three volumes, an appendix, a supplemental appendix and a volume of exhibits. A copy of these volumes (which have been bound together) have been lodged with this Court. Page references in this brief prefixed by the letter "A" refer to the appendix; "SA" to the supplemental appendix; and "E" to the volume of exhibits.

myelomeningocele (spina bifida),[2] hydrocephalus,[3] microcephaly,[4] bilateral upper extremity spacticity, prolapsed rectum and a malformed brain stem.

Her parents were fully informed of their child's medical condition and prognosis (E. 41, 52; A. 280-284). They were informed of the risks and potential benefits associated with the two medically acceptable forms of treatment—performing dual surgical procedures or maintaining a conservative medical treatment (E. 41, 51, 53). The record showed, as noted by the Appellate Division, that while the failure to perform surgery would not have placed the infant in imminent danger of death, surgery might have significantly reduced the risk of infection. On the other hand, successful results were also possible with antibiotic therapy. "[W]hile the mortality rate is higher where conservative medical treatment is used, . . . the surgical procedures [proposed] also involved a great risk of depriving the infant of what little function remained in her legs, and would also have resulted in recurring urinary tract and possible kidney infections, skin infections and edemas of the limbs." *Weber* v. *Stony Brook Hospital*, 95 A.D.2d 587,

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2. Myelomeningocele is a failure of the bones surrounding the spinal cord to close fully (E. 36). As a result, the spinal cord and the surrounding membrane protrude from the child's back (E. 82). The effect of this condition on Baby Jane Doe included failure of rectal function; failure of bladder function; very restrictive leg function; and limited sensation (E. 37).

3. Hydrocephalus is fluid in the cranial cavity causing an enlargement of the head (E. 58). This condition, in combination with the microcephalic condition indicates an "extremely high risk for profound and severe retardation . . ." (E. 65).

4. Microcephaly is characterized by an unusually small head and brain at birth (E. 38, 69). The condition is a result of a failure of the brain to form properly (E. 69). As a result, Baby Jane Doe is severely retarded (E. 65).

589 (2d Dep't 1983), *aff'd*, 60 N.Y.2d 208 (1983). After extensive consultation with the treating physicians, family and clergy, the parents decided against the dual surgical procedure and opted instead for the conservative medical treatment (E. 53).

On October 18, 1983, HHS filed a complaint with the New York State Child Protective Service ("CPS") alleging neglect in the care and treatment of Baby Jane Doe. The Child Protective Service, the state agency created by the Federal Child Abuse Protection and Treatment and Adoption Act specifically to explore suspected instances of child abuse and neglect, fully investigated the allegations. It concluded that the complaint was unfounded and that there was no cause for state intervention or further action (A. 290).

On October 16, 1983, immediately prior to the CPS inquiry, a proceeding was commenced in the Supreme Court, Suffolk County seeking appointment of a guardian *ad litem* for the infant and an order directing that surgery be performed. After a trial, the state judge ordered surgery. The New York State Supreme Court, Appellate Division, First Department, unanimously reversed and dismissed the proceeding, finding that the treatment given Baby Jane Doe was medically appropriate:

> It is manifest, therefore, that this is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. Rather, it is a situation where *the parents have chosen one course of appropriate medical treatment over another.* These concededly concerned and loving parents have made an informed, intelligent, and reasonable deter-

> mination based upon and supported by responsible medical authority.
>
> On this record, and in light of all the surrounding circumstances, we find the parents' determination to be in the best interest of the infant. Accordingly, there is no basis for judicial intervention (emphasis added).

95 A.D.2d at 589.

The Court of Appeals of the State of New York affirmed the Appellate Division on different grounds. At the outset, the court stated, "This case involves a situation in which the parents of a new born infant, in consultation with others, had *responsibly* decided upon a course of medical treatment" (emphasis added). *Weber* v. *Stony Brook Hospital*, 66 N.Y.2d 208, 210 (1983). Upon review of the entire record, the court found "no justification for resort to or entertainment of the [state court] proceedings." *Id.* at 213. In particularly harsh language, the court declared, "[T]here are overtones to this proceeding which we find distressing. Confronted with the anguish of the birth of the child with severe physical disorders, these parents, in consequence of judicial procedures for which there is no precedent or authority, have been subjected in the last two weeks to litigation through all three levels of our State's court system." *Id.* at 213. The court found, "[I]t would serve no useful purpose at this stage to recite the unusual, and sometimes offensive, activities and proceedings of those who have sought at various stages, in the interests of Baby Jane Doe, to displace parental responsibility for and management of her medical care." *Id.* at 211.

Finally, the court noted that the New York State Legislature, in enacting the Family Court Act, had made avail-

able a satisfactory procedure to protect children when government intervention is necessary.

> "Article 10 of the Family Court Act is expressly 'designed to establish procedures to help protect children from injury in mistreatment and to help safeguard their physical, mental and emotional well-being. It is designed to provide due process of law for determining when the state, through its Family Court, may intervene against the wishes of the parent on behalf of the child so that his needs are properly met' (Family Court Act § 1011)."[5]

Id. at 211-12.

Notwithstanding the close scrutiny already given to the care of Baby Jane Doe by the state courts and child protection agency, HHS, which was already in possession of at least a substantial portion of Baby Jane Doe's medical records through October 19th,[6] demanded copies of her medical records from the hospital on October 22, 1983. The hospital denied the request, basing its decision, in part, on the fact that the infant's parents had advised the hospital that they did not consent to allow HHS to have access to these confidential records.

On November 2, 1983, the United States filed an action in federal district court to obtain the medical records. After a hearing, defendants were granted summary judg-

5. Pursuant to the Family Court Act, a complaint may be made to the Child Protective Service, which maintains a 24 hour hotline. If warranted after investigation, the CPS may commence a child neglect proceeding seeking immediate court intervention. (N.Y. Family Court Act § 1032 [McKinney 1975]). The court, on its own, may also cause a child neglect proceeding to be commenced.

6. These medical records were not provided to HHS by either University Hospital or Baby Jane Doe's parents.

ment.[7] *United States* v. *University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984). The district court reviewed the record to determine whether University Hospital violated the statute by discriminating against a handicapped person. It found that the parents of the child had refused to consent to the performance of the operation but had instead opted for conservative medical treatment, *id.* at 614-15, that the hospital had been willing at all times to allow the surgical procedures to be performed if the parents would consent to such procedures, *id.* at 614, that the hospital lacked the legal right to perform surgery without the consent of the parents or legally appointed guardian and that the child was receiving medical treatment, including good nutrition, antibiotics and dressing of the spina bifida. *Id.* The district court based these findings on its review of the record in the state court proceedings, including the findings of the New York Court of Appeals and Appellate Division, the conclusion of the Child Protective Service, and the affidavit of the hospital administrator that the child was not being neglected and that the parents had acted responsibly in their choice. On the basis of this factual record the court held that:

> . . . the papers submitted to the Court demonstrate conclusively that the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child.

Id. at 614-15.

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7. The trial court entered summary judgment for defendant, despite the fact that defendant did not specifically move for summary judgment, upon the court's finding that no factual dispute existed and that the non-movant was entitled to summary judgment as a matter of law.

Consequently, the court concluded that HHS was not entitled to access to the confidential medical records. It found that the failure of the hospital to perform the surgical procedures in these circumstances was in conformance with its legal obligation not to perform surgery without the consent of the child's legal guardians and "cannot possibly be regarded as a violation of the Rehabilitation Act's prohibition against subjecting a handicapped individual to discrimination solely by reason of her handicap." *Id.* at 614.

The Court of Appeals for the Second Circuit affirmed the lower court's decision. It noted the federal government's principal argument that the lower court erred in concluding that the parents' refusal to consent to surgery conclusively established the hospital's nondiscrimination and thus insulated the hospital from liability under Section 504. The court also noted that the government claimed, for the first time on appeal, that the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents' decision and compelling surgery was itself a violation of the nondiscrimination requirements of Section 504. Thus, it was clear to the Second Circuit that the government's investigation proceeded on the assumption that the government was empowered by Section 504 to review medical treatment decisions made by parents. Importantly, the Court of Appeals rejected that view:

> . . . in arguing that Baby Jane Doe may have been "subjected to discrimination" the government has taken an oversimplified view of the medical decision-making process. Where the handicapped condition is related to the condition(s) to be treated, it will rarely,

> if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent, breaks down. Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment", however, that phrase might be defined. Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.

729 F.2d at 157.

Finally, the court found that it could not simply presume that Congress intended the federal government to enter the field of infant care, traditionally occupied by the states pursuant to their police power, to oversee judgments historically made by parents and their doctors.

2. The University Hospital Case Demonstrates That HHS's Review Of Treatment Decisions Concerning Handicapped Infants Is Unwarranted And Impedes A Hospital's Ability To Provide Effective Medical Care.

Both the federal investigation into the care of Baby Jane Doe and the HHS regulations are founded on the premise that physician and hospital care for handicapped infants is so callous and deficient as to require federal supervision. As the facts of the Baby Jane Doe case demonstrate, this premise is false. The record before the federal district court in *University Hospital* depicted a hospital with compassionate, competent staff, caring for a

severely handicapped child in accordance with informed medical judgment and the child's best interest. The record demonstrates that the decision as to the course of treatment for the infant was made by the parents in consultation with the treating physician. The hospital was prepared to allow the operations to be performed if requested by the parents.

The experience of University Hospital highlights the effectiveness of the existing comprehensive state scheme for reviewing infant care by trained experts, pursuant to specific statutory and regulatory procedures. The child protective agency and the state judiciary reviewed the care being provided and concluded that it was medically appropriate. Despite prior knowledge of these findings the federal government, without any further evidence, interjected itself into the already settled question of the infant's care. This resulted in severe hardship to the child's parents, the hospital staff and the treating physicians and an unwarranted interference with the effective operation of University Hospital.

If the challenged regulations are permitted to be implemented, these harmful intrusions into the care of children with handicapping conditions will become commonplace. The Second Circuit properly concluded that such broad-ranging federal intrusion should not be permitted except upon an express direction by Congress, based upon its assessment of the policy concerns implicated by allowing the federal intrusion into traditional doctor-patient relationships:

> it is congress, rather than an executive agency, that must weigh the competing interests at stake . . . Until

> congress has spoken, it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.

729 F.2d at 161.

B. There Is No Authority Under Section 504 For The Federal Government To Review Medical Treatment Decisions.

1. Legislative History and Statutory Interpretation.

The legislative history of Section 504 does not support the Secretary's expansive interpretation of that statute. Exhaustive review of the legislative history, the Second Circuit declared, "indicates that congress never contemplated that section 504 would apply to treatment decisions of this nature." *United States* v. *University Hospital*, 729 F.2d at 157. *See also American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 394, 402 (D.D.C. 1983) (no committee or member of the Congress even suggested that Section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life).

The Court of Appeals, in addressing the petitioner's argument on statutory authorization, noted that:

> [T]he government's theory not only strains the statutory language but also goes well beyond congress's overriding concern with guaranteeing handicapped individuals *access* to programs or activities receiving federal financial assistance. Further, the situation is dramatically different in kind, not just degree, from the applications of section 504 discussed in the legislative history. Under these circumstances, the failure

> of congress to focus on *treatment decisions* involving defective newborn infants strikes a telling blow to the government's position (emphasis added).

729 F.2d at 159-60.

Petitioner relies upon Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000 *et seq.*, to supply for its argument what Section 504's legislative history does not, but this reliance is unavailing. Section 504 was assuredly patterned after Title VI, but there is no indication that Title VI reaches *medical decisionmaking* among alternate treatment options, as opposed to outright denial of equal treatment due to one's status. Petitioner's failure to make this distinction is telling and her reliance upon the dissent in *University Hospital* and the analogy presented therein is therefore misplaced. (Pet. Brief p. 11).[8]

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8. Indeed, the circumstances suggested by Judge Winter which would warrant the invocation of the Secretary's authority under Section 504 are so unlikely to eventuate that they offer little by way of instruction. A decision by a hospital to withhold medical treatment when requested by a handicapped infant's parents simply is unlikely to occur. A refusal to treat at all, upon request, would be a denial of equal access. Petitioner has not cited the Court to one instance in which a hospital receiving federal financial assistance has refused to provide medical treatment to a handicapped infant where the parents had requested it.

The more likely occurrence is the parents' refusal to consent to a particular course of aggressive treatment for their impaired infant. Where medical personnel at the hospital disagree with that determination, they may commence judicial action or contact the appropriate child protection agency. Indeed, this is precisely what occurred with the newborn child with Downs Syndrome who died in Bloomington, Indiana. The hospital sought judicial intervention. The state courts that reviewed the matter, however, determined that the parents had made a reasonable decision among treatment options. The local welfare agency reviewed the case and decided not to challenge the court's order. In a second action brought by the county prosecutor, the court found no parental neglect. *See In re Infant Doe,* No. GU 8204-004A (April 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker,* No. 4825140 (Ind. May 27, 1982).

A decision by a hospital receiving federal financial assistance not to perform surgery on an individual because of his race raises a question of access based on a proscribed criterion. Such an action by the hospital would clearly be prohibited. Similarly, an action by a hospital to deny admission to a handicapped child solely because the child is handicapped is a violation of the Rehabilitation Act. On the other hand, as the majority's decision noted,

> Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent breaks down.

729 F.2d at 157. The medical treatment decisions which HHS would review if this Court upholds the regulations are likewise related to the handicapping condition itself. HHS's ideological preference for a particular course of treatment does not raise a question of denial of access. To assert otherwise is in essence to argue that Congress had decreed a uniform manner of medical treatment for all impaired infants, irrespective of the judgments of doctors and patients' families. There is not a shred of legislative history or textual support for this proposition.

Petitioner attempts to minimize the obviously disruptive consequences of its expansive reading by conceding that "Section 504 does not provide for 'second guessing of reasonable medical judgment regarding medically beneficial care'" (Pet. Brief, p. 4) and that "[i]n determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgment will be

respected." *Id.* Although petitioner argues that "the regulations and guidelines the court of appeals invalidated do not intrude the Secretary into complex medical judgments made by health care professionals", (Pet. Brief, p. 16), the regulations clearly portend the Secretary's interventionist role in determining the reasonableness of any particular medical judgment and imposing her view as to the appropriateness of a particular course of medical treatment. Thus, the regulations provide for the Secretary's expedited access to records and facilities of the recipient hospital for investigative purposes when "necessary to protect the life or health of a handicapped individual." 45 C.F.R. § 84.55(d). There could hardly be a clearer indication that *direct* intervention by the Secretary is foreseen even where the treatment may be based upon the reasonable medical judgment of the primary health care provider.

The Secretary's interest in overriding "reasonable medical judgment" with which the government disagrees is concretely demonstrated by her actions in the *University Hospital* case.[9] When the Secretary attempted to obtain Baby Jane Doe's medical records on November 2, 1983, a guardian *ad litem* had already been appointed to protect the interest of the infant and extensive adversarial proceedings had been completed in state court which approved the reasonableness of the parents' decision.

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9. Petitioner suggests that the Court of Appeals, by issuing a nationwide injunction without waiting for the Secretary to consider the regulation's application in any specific instance, foreclosed her from demonstrating the "flexible" application of Section 504 on a "case-by-case basis, with a sensitive regard for the circumstances presented." (Pet. Brief, p. 15). The Secretary's actions regarding her attempted involvement in the treatment decision of Baby Jane Doe, however, demonstrate her *lack* of sensitivity with regard to the application of the statute.

It is simply disingenuous for the government to argue against this backdrop that it is not seeking to "second guess" reasonable medical judgments or that it would "respect" reasonable medical judgment to select a particular course of treatment for an impaired infant from available alternatives. Congress has not indicated any intent to accord the Secretary the broad and intrusive power she seeks. Unless and until Congress indicates its support for the broad view taken here by the Secretary, there is simply no authority for the Government to override parents' choice of available medical treatment options.

2. HHS's Previous Interpretations of Section 504.

Prior to May, 1982 when the Secretary issued a "notice" to health care providers "to remind affected parties of the applicability of Section 504," HHS, as well as its predecessor, the Department of Health, Education and Welfare ("HEW"), agreed that the statute could not be used as a basis for federal intervention in medical decisionmaking concerning any individual. It was well understood that there was no warrant for federal oversight of medical treatment decisions made by parents of seriously ill infants in consultation with their doctors.[10] Instead, the focus of the agency's original regulations was on the "[a]vailability of

10. In its original notice of intent to issue proposed rules under Section 504, HEW sought comment on certain "critical issues" including whether a regulation should contain provisions regarding a patient's right to receive or refuse treatment. 41 Fed. Reg. 20296 at 20297. Subsequently, HEW concluded "that the department did not have authority to regulate in this area" and that "[t]he Secretary is of the opinion that to promulgate rules on these subjects is beyond the authority of section 504." 41 Fed. Reg. 29548 at 29559.

services" and the accessibility of such services to handicapped persons who desired them. *Id.* at 29567.[11]

As the Second Circuit noted, "[i]t was not until five years later (after the initial regulations were adopted in May 1977) that HHS first took the position that section 504 made it unlawful for hospitals receiving 'Federal Financial assistance' to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition." *United States* v. *University Hospital*, 729 F.2d at 152. *See also American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. at 397. The court concluded that "HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW." *United States* v. *University Hospital*, 729 F.2d at 154.

Petitioner's characterization of the former regulations as supportive of the government's position is simply misleading (Pet. Brief, pp. 2-8, 16-18). The examples cited involve patient access to health care facilities for desired treatment, not the Secretary's involvement in the choice of various treatment decisions made by families and their doctors. Thus, the example of a burn treatment center refusing to treat the burns of a deaf person because of his or her deafness (Pet. Brief, p. 40), *see* 45 C.F.R. Pt. 84 App. A para. 36, illustrates denial of *access* because of one's

11. Under the general provision for "health, welfare and social services," the regulations proscribed denying a qualified handicapped person such services, 45 C.F.R. § 84.52(a), or denying them "the opportunity to participate in or benefit from the aid, benefit or service." 45 C.F.R. § 84.4(b)(1)(i). HHS's analysis of these regulations stressed "the basic requirement of equal opportunity to receive benefits or services." *See* 45 C.F.R. Part 84, Appendix A, ¶ 36. Thus, these regulations recognized the purpose of Section 504—the guaranteeing equal *access* to handicapped persons—and properly excluded review of medical treatment decisions.

handicap. The same is true of the denial of treatment to an alcoholic or drug addict by a federally assisted hospital because of his condition. (Pet. Brief, p. 37). Equating a prohibition of denial of access to medical care because of one's status (*e.g.*, race or handicap) with oversight of medical treatment decisions made by families and their doctors, as petitioner has done, is pure sophistry and mischaracterizes the substance of early regulations.

C. The Damaging Effects of Federal Intrusion Into Private Medical Treatment Decisions.

1. The Regulations Would Prevent Physicians From Exercising Their Professional Medical Judgment In Advising The Parents Of Seriously Impaired Infants.

The challenged regulations, as demonstrated by HHS's actions in the *University Hospital* case, would reverse the normal presumption of validity afforded professional medical judgments. *See Youngberg* v. *Romeo*, 457 U.S. 307 (1982), vacating and remanding, 644 F.2d 147 (3d Cir. 1980). The standard contained in the regulations—whether treatment rendered was "medically beneficial" as determined by "reasonable medical judgments"—would impose a nationwide "negligence" standard upon medical treatment decisions which would predictably lead to federal second guessing and even overriding of the medical judgment of the treating doctors.

Under the regulations, every routine medical treatment decision involving handicapped infants admitted to a re-

cipient hospital has the potential of becoming the subject of lengthy litigation pitting the treating physician against the federal government as to the meaning of a "reasonable medical judgment". Such litigation would undoubtedly subject a hospital's medical and health care services, as well as its physicians and administrators, to intensive and unwarranted scrutiny by unrelated individuals, the media and public officials. In the instance of Baby Jane Doe, University Hospital had to take unusual precautions to protect her privacy and that of her parents, including the assignment of additional security to the neonatal intensive care unit where the infant was located. The hospital was bombarded with telephone calls from individuals seeking information and offering opinions about the treatment of the infant (ranging from an inquiry by Surgeon General Koop, who contacted a member of University Hospital's medical staff to discuss the case, to a request to adopt Baby Jane Doe from an individual claiming to be a well-known movie star).

As a result of these actions physicians were compelled to provide treatment in a fishbowl; the hospital atmosphere became highly charged with suspicions of neglect and medical malpractice. This environment is not only demeaning and potentially intimidating to the responsible professionals, but may actually interfere with their making appropriate decisions relating to medical care. Health care professionals may perform too many, lengthy or expensive tests and procedures, administer unnecessary drugs, or even spend too much time considering available alternatives. This may be harmful not only to the patient in the spotlight but to other patients as well if attention is drawn

away from their needs. Indeed, the federal review of medical treatment decisions could subject handicapped infants to unintended discrimination if, in response to unwise regulation, surgical alternatives are chosen to avoid subsequent claims that "medically beneficial treatment" was not rendered and to prevent litigation over whether "reasonable medical judgment" was exercised.[12]

A courtroom battle between experts over what constitutes medically "beneficial" treatment or "reasonable" medical judgment is precisely what this Court sought to prohibit in *Youngberg* v. *Romeo*. This prohibition is particularly compelling where the judgment as to the appropriate treatment is concurred in by the physician and the infant's parents. The appropriate standard of review should not be more intrusive than whether medical judgment was exercised. Congress did not intend to spawn litigation over the course of medical treatment chosen when it enacted Section 504. *United States* v. *University Hospital*, 729 F.2d at 160.

2. The Regulations Would Displace The Right And Responsibility Of Parents To Make Medical Treatment Decisions In The Best Interests Of Their Children.

In the federal action involving Baby Jane Doe, the United States persisted, in the face of carefully considered decisions by the state courts, the state child protective agency, the treating physicians, and most importantly, the loving and concerned parents, in attempting to impose

12. For example, if Baby Jane Doe had been forced to undergo immediate surgery for the spina bifida she might have lost all function in her legs. (E. 74).

its view that Baby Jane Doe's spina bifida must be treated with surgery. The invalidated HHS regulations would permit innumerable repetitions of such harassment.

This Court has recognized that parents, in making difficult treatment decisions involving their children, will presumably act in the best interests of those children. In the absence of a showing of abuse, that presumption should be respected. *Parham* v. *J.R.*, 442 U.S. 584 (1979). The invalidated regulations would require that health care providers always seek to impose an aggressive course of medical treatment as being in the best interest of the child. *Ipso facto,* such a mechanical rule would often times override parental treatment decisions made after consultation with their physicians.

The parents of Baby Jane Doe, who were subjected to an investigation by the child protective agency and to litigation through all three levels of both state and federal court, were consistently found to have been acting in the best interests of their child, in selecting a conservative course of medical treatment. They chose, relying on the sound professional judgment not to authorize an operation to close the spina bifida lesion, but instead to have it dressed surgically. By mid-December 1983, the spinal defect had closed spontaneously without surgical intervention vindicating their decision. *See* Baby Jane Doe at Stony Brook: A Chronology; Treatment of Newborns: Medical, Ethical and Social Issues. State University of New York at Stony Brook; October 17-20, 1984, p. 3.

Conclusion

The decision of the United States Court of Appeals invalidating the proposed HHS regulations should be affirmed.

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Respectfully submitted,

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